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ABSTRACT

This report of proceedings includes a keynote address "Prevention of Mental Retardation Circa 1983" (G. Tarjan) and eight papers from a keynote panel. Papers include: "Genetic Issues" (G. Oakley); "Impact of Intervention on High-Risk Children" (J. Gallagher); "Perinatal Issues" (G. Avery); "Social Issues" (J. Mercer); "Feasible Goals for Prevention of Mental Retardation and Other Developmental Disabilities" (H. Moser); "Prevention of Developmental Disabilities: Fundamental Considerations for Public Policy" (A. Crocker); "Prevention of Developmental Disabilities: Federal Action" (J. Elder); and "Prevention of Developmental Disabilities: Model State Plan" (R. Guthrie). Following these papers is an address entitled "Prevention in Virginia" by Virginia state governor Charles Robb. Workshop discussions are then summarized for 16 topic areas, including statewide genetic and perinatal care services, prevention of preterm births, newborn and infant screening, environmental hazards of early childhood, and prevention of child abuse and neglect. More than 125 recommendations are made regarding genetics, perinatal health, early childhood, and administration and philosophy. Concluding remarks and comments summarize Virginia's progress and present reactions of state officials to the recommendations. (CL)

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Action for Prevention

PROCEEDINGS

Mental Retardation/Developmental Disabilities Prevention Conference

Williamsburg Hilton
Williamsburg, Virginia

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"ACTION FOR PREVENTION"

1983 Virginia Mental Retardation/Developmental Disabilities Prevention Conference

Williamsburg National Conference Center
December 14-16, 1983

Sponsored by
The Association for Retarded Citizens in Virginia
The Virginia Department of Mental Health and Mental Retardation
Office of Prevention and Information Services
Virginia Developmental Disabilities Planning Council
Virginia Commonwealth University
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Acknowledgments

The conference and this proceedings came about through the labors of a number of people. All of the individuals whose names appear later in this manuscript under the title Conference Planning Committee gave generously of their ideas and energy, many of them for more than a year, out of genuine concern for the cause of prevention. Without their efforts, the conference would not have been possible. Among that committed band, however, a few stand out for special recognition and thanks: Howard Sparks, for guiding our efforts with insight born of experience; Marcia Penn, for always giving more than she asked and for refusing to acknowledge impossibility; Ruth Kavanaugh, for wit that survived countless drafts; and John Pezzoli, for working tirelessly to pull together a program of distinction and depth, and to both Ruth and John, for the care and wisdom that shaped the Action Agenda; Lisa Poe, for commitment, persistance, and kindness; Phoebe Harcum, whose keen attention to detail allowed the rest of the committee to sleep at night; Linda Valdheer, who has recognized for a long time the harmony of intent between those who strive to prevent disability and those who work to help the developmentally disabled choose their own paths; Meade Boswell, whose grace under pressure and good sense buoyed us all; Earl Agee, for gracious eleventh hour assistance; and Barbara Kniest, last but hardly least, the calm voice of reason and order behind registration. Finally, none of this would have been possible without the extensive support and endorsement of the Association for Retarded Citizens of Virginia, the Virginia Department of Mental Health and Mental Retardation, the Virginia Developmental Disabilities Council, and Virginia Commonwealth University, who forged an uncommon alliance for a common goal.

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INTRODUCTION

by Howard L. Sparks
Conference Chairman

The 1983 Virginia Mental Retardation Developmental Disabilities Prevention Conference brought together over 400 persons, from across Virginia and the nation, committed to the prevention of developmental disabilities and mental retardation. During the three days, the conference participants discussed intensively and debated how genetic, perinatal, early childhood, economic, and other factors, such as barriers to service delivery and divergent philosophies, contribute to the incidence of developmental disabilities. More importantly, the discussions went beyond causes of developmental disability to center on practical prevention strategies. The Williamsburg prevention conference generated over 125 recommendations for actions that can and should be taken in Virginia in a coordinated effort to reduce the incidence of developmental disabilities.

The prevention conference, jointly sponsored by the Virginia Association for Retarded Citizens, Virginia Department of Mental Health and Mental Retardation, Virginia Developmental Disabilities Planning Council, and Virginia Commonwealth University, reflects a degree of interagency cooperation that is highly unusual and bodes well for future prevention efforts. The conference is, in fact, but one in a series of activities and actions taken in Virginia in the last decade that reveals an increasing awareness of the potential for the prevention of disability and an increasing desire to see that prevention is undertaken in a more systematic and effective manner.

While we can be proud of the level of commitment to prevention that exists, we must recognize that much work remains. This document contains transcripts of each plenary session, a summary of each workshop session, and the recommendations for prevention -- the *Action Agenda* -- generated by the conference. Taken together these proceedings give an account of the discussions and presentations at the prevention conference. But the proceedings also do something else. As you read them, I believe you will sense at least a hint of the tremendous excitement and dedication felt by the conference participants. The variety of topics covered, the level of interest shown, and the clear evidence that further action is feasible, all contributed to a powerful sense of readiness to act on the part of those who attended.

With a group of dedicated citizens as skilled and determined as those who attended the Williamsburg prevention conference, one anticipates that the lives of all citizens of the Commonwealth will be enriched. As professionals from mental health, medicine, psychology, education, social work, nursing, and the basic sciences shared information, it was an exhilarating experience to become aware of the "state of the art" in preventing mental retardation and developmental disabilities; it was informative and certainly motivating to see the diverse professional groups coalesce so readily.

To capture the full spirit of the conference and the great enthusiasm of all participants is difficult. The Action Coalition, which was formed at the closing session, is the best testimony to the success of the meeting and the determination not to be deterred as an agenda for the next decade is developed.

And action will occur. The participants clearly affirmed their determination to seek changes, and therefore changes will come. Some will come rapidly -- some more slowly. Some will be administrative, some will be legislative. All, however, will require the continued enthusiasm so apparent in Williamsburg. An important flame has been lit and it must not be allowed to flicker.

Most conferences are finished when they end. This one, instead, is a *beginning*. The end of the conference merely marked the time when participants returned to sites all over the Commonwealth and the nation, sites from which action for prevention will grow and progress. As you read and consider the material contained herein I hope that you, too, will be inspired to look for the part that you can play in this effort.

CHARGE TO CONFERENCE

by Joseph L. Fisher, Ph.D.
Secretary of Human Resources
Commonwealth of Virginia

We have great hopes for this conference, which aims to secure action on a worthy agenda. When knowledge and emotional drive are hitched to practical actions in a worthy cause, then look out, because something is going to happen--you can be sure of it--and that I believe is the situation we find ourselves in here, right now. A few minutes ago, I was talking with a friend and got my metaphors mixed up and said, "Thinking of prevention, do not forget a stitch in time is worth a pound of cure." Think about that for a minute. I suppose I could have said, "An ounce of prevention saves nine."

The conference goal is: to develop and begin implementation of an *action* plan to prevent mental retardation and developmental disabilities to the greatest extent possible, by the end of this century, within political, economic, scientific, programmatic, and ethical considerations. Now each of these considerations has to be kept in mind, but all of them together should not be allowed to discourage or to delay our moving forward immediately against the problems of mental retardation (MR) and developmental disabilities (DD).

Renewed Emphasis

Let us look at each of these considerations, the political, the economic, the scientific, the programmatic, and the ethical. It does seem to me that the time is ripe, probably overripe, for a renewed emphasis on prevention of MR/DD. As for political considerations, well, what politician can be against prevention? Might as well be against apple pie or the Washington Redskins. Economic considerations--prevention is relatively cheap, very cheap, compared to curing. And these are the times of the budget crunch. Scientific considerations--medical scientists and practioners alike are ready with all manner of new techniques for prevention and for amelioration, as are the educators, the psychologists, and the social workers. Programmatic considerations--some programs are already in place, for example, what we call the Better Beginnings program. Others, I am confident, will come out of the exciting deliberations of this conference. Ethical considerations--even the ethical conundrums and

dilemmas associated with Baby Doe, right to life versus freedom of choice, death with dignity, and so on, even these are being debated, and people more and more are looking for resolution and for agreement.

The stage is set. The experts are ready or ready enough. The decision-makers cannot put off decisions much longer. I believe prevention's time has come and probably come in a big way. Preventive action is the thrust of this conference.

Patricia Harris, the former Secretary of Health and Human Services and chairman of the President's Committee on Mental Retardation, wrote in the letter of transmittal of that committee report that many cases of mental retardation are preventable. Experts in the field tell us that of the 200 known causes of mental retardation, including injuries at birth, inherited toxic conditions, genetic factors, measles, diabetes, x-rays, lead and household poisonings, metabolic disorders, Rh blood diseases, and so forth, more than 50 percent are preventable. Experts have found that a large percentage of mental retardation resulting from environmental influences, including sociocultural disadvantages, poor housing, poor diets, and poor living habits, is preventable. That opens up quite a prospect for action. We must not fail to seize it.

MR/DD Statistics

Here are a few statistics about MR and DD in the United States and in Virginia:

1. Over 200 causes of MR have been identified, and one out of every 10 persons has a mentally retarded person in the family.

2. Of 78,000 births occurring in Virginia in 1982, an estimated 2,500 to 3,700 individuals will be considered mentally retarded at some point in their lives.

3. Six hundred thirty-three babies were born in Virginia in 1982 with congenital abnormalities, many with associated mental retardation and other developmental disabilities.

4. Nearly 6,000 babies were born in Virginia in 1982 with low birthweight and, therefore, many of them are high risk for mental retardation.

5. In 1981, Virginia's infant mortality rate was 12.6 per thousand live births, and the incidence of MR of biomedical origin is higher than in 31 other states.

6. More than half of the mental retardation in this country is almost completely preventable. Approximately one in 700 children

suffers from fetal alcohol syndrome. More than 150,000 children under 14 in this country are injured yearly in car accidents. The two most common injuries are head trauma and spinal cord damage, both leading to developmental disabilities. An estimated 60 to 75 percent of these injuries could be prevented through the use of seat restraints: belts, air bags, and so forth. Many more in the 14 to 24 age bracket are also injured in accidents. In 1983, an estimated 675,000 American children, between six months and 5 years of age, were affected by lead poisoning, one of the causes of mental retardation and other abnormalities. And I could go on. The list is distressingly long.

As you know, MR and DD have been given increasing attention in recent years. Back in the early 1960s President Kennedy and those associated with him in this field gave tremendous impetus to more effective programs in the MR/DD field. Here in Virginia in 1976, a committee studying the preventable causes of mental retardation reported to the governor and the General Assembly that it was essential that the Commonwealth of Virginia actively undertake programs to prevent mental retardation in order to be properly responsible to its citizens, to fulfill its humanitarian aim to reduce suffering, to improve the quality of life, and to relieve its tax payers of the financial drain, which each unnecessary instance of mental retardation necessitates.

Governor Robb has singled out prevention as a priority during his administration. This includes more attention to community and home-based care and training for jobs and independent living. He also stresses the widest possible citizen participation in the prevention of MR and DD and in other human resource programs.

Conference Objectives

The goal of this conference is to develop and begin implementation of an Action Agenda for Virginia to prevent developmental disabilities.

Specific objectives have been put before you:

1. Formation of a statewide coalition for MR/DD prevention

2. Promotion of wider understanding of prevention strategies through an exchange of information and presentation of current research

3. Development and implementation of the MR/DD prevention action program

Prevention of MR has been called the other side of the divided house. Virginia has done quite well, on the relative scale, in addressing the

needs of her developmentally disabled citizens, but not in preventing them. Not yet. We must show the same concern for prevention that we accord to training. We are remiss in decrying the tragedy frequently associated with mental retardation if we are unwilling to do more in preventing its occurrence.

One purpose of the conference is to exhort the individual conscience, the most powerful source of change that there is. Prevention is our common concern, each individual's responsibility. You can make a difference. Each and every citizen can make a difference. De-institutionalization, special education, legislation--each of these milestones in the care and training of the mentally retarded resulted largely from the efforts of concerned citizens and professionals like yourselves. You can have an equal influence in prevention, of that I am sure.

The planning of this conference has involved, already, an alliance of individuals, public agencies, and private groups. Prevention, therefore, is a nonpartisan issue calling for a combined attack. We have to work together.

In the next few days we will hear from researchers, educators, caseworkers, and others in the field of MR and DD. We will hear in detail what can be done, given our current technology and expertise, to prevent as much as half of all mental retardation. You will be developing a state Action Agenda, setting forth a comprehensive approach to the problem. We may not necessarily be able include all that you would like to include, or to do it all right away; but do not let that stop you. Be bold. Be specific. Press your case with the administrators, the politicians, those who hold the purse strings. There can be no excuse for not striving to do the very best we can in a cause that everybody will agree is a necessary cause, a noble cause, one that must succeed. Just remember, a stitch in time is worth a pound of cure.

Keynote Address

Prevention of Mental Retardation Circa 1983

by George A. Tarjan, M.D.
Department of Psychiatry and Biobehavioral Sciences
UCLA School of Medicine

During the time allotted to me I will address seven topics. I will first make some personal historical comments, essentially because I have been around for a long time, secondly because my age permits me to say what I mean to say. I will then make some general historical comments to enumerate the forces of change that have produced what we have today, comment on progress to date, on this meeting, on prevention, and close with two admonitions. Let me, therefore, first turn to some personal historic comments.

Historical Comments

I got into the field of mental retardation some 36 years ago when I returned from the Southwest Pacific and became certified in psychiatry. Flying at that time from Columbia University to Peoria, Illinois, I made a wise decision, which was to move to California; and I thought to myself at that moment that here I was an expert in the human mind, but I knew nothing about one of its most severe and serious anomalies, mental retardation. No one taught me anything about it, no one asked me any question about it. So I thought that before I followed the usual pattern of psychiatric practice in southern California--which meant settling at Clutch Canyon and, with a Hungarian accent and blonde hair, practicing psychoanalysis--I ought to find out something about mental retardation. I was recruited by the California state system and, because I was certified, I was made clinical director, which meant I was to teach others about retardation. I read both books available at that time and knew even less.

Ten years later, I became the president of the American Association of Mental Deficiency. My presidential address, now 25 years ago, was titled "Prevention: A Program Goal in Mental Retardation." My good colleagues congratulated me and said my presentation was erudite, scholarly, dreamy and wooly-headed. But I decided to stick with prevention. In fact, I selected that topic because in the preceeding 10

years I thought that my colleagues and I instituted many new service programs. We already had, at that time, a preadmission clinic which assesssed needs for services, reasons for admission, and protocols for intervention. We were in the midst of trying to find out what happened to institutional populations. We already had a very large community-based program which we called Family Care, and I thought to myself that the next critical item in the field of retardation that must be addressed was prevention. But in spite of that, my comments were considered dreamy and wooly-headed. I emphasize this fact to point out to you how far we have come in a quarter century. I spoke about prevention three times at international congresses on child psychiatry. I spoke about prevention in lesser developed countries in many parts of this globe. My presidential address to the American Academy of Child Psychiatry was on the prevention of psychosocial retardation.

The Field of MR Since 1947

Let me now turn to some general comments and let me tell you that these comments are made particularly to younger colleagues in the room, who have no knowledge or insufficient knowledge, to point out how far the Commonwealth of Virginia and how far this nation have come during my career in the field of retardation. In 1947, the field institutions were essentially the only out-of-home care places for mentally retarded individuals. They were overcrowded, they were understaffed, and they were underbudgeted, and, in spite of these facts, they had a waiting list for admission which was regulated only by the queuing phenomenon. The average parent was willing to register if there was any chance of admission for the child within three years and did not do so if the waiting period was longer. Within the institution, we had no idea which classes of patients were apt to die, which classes of patients were apt to become sick, or which were likely to get out alive. We had no idea which had neuromuscular impairments as a class of patients, or which had seizure disorders.

The institution was chock full of what I used to refer to as "institutional superstitions." There was a firm belief that Down's syndrome youngsters could do nothing. In those days, we used to say the Mongoloid patient was suited only for sitting and smiling. As a consequence, most of them did nothing but sit and smile. Out of necessity, the staff at Pacific State Hospital, as it was then known, began experiments to seek out capabilities rather than impairments of Down's syndrome youngsters. We found that, in fact, they were superb feeders of more impaired patients, particularly those with cerebral palsy, because they positioned them better, they hugged them, and they performed the feeding task at a slower rate. That was my first claim to fame because someone in the nation's capital heard about that crazy Hungarian who had the notion that Down's syndrome youngsters could perform useful tasks.

We had no notion either about Down's syndrome youngsters' life expectancy and, in fact, believed that they did not have seizures, which I presume came out of the psychiatric superstition that schizophrenia and seizures do not mix, from which, on an incorrect basis, the original shock treatment notion was developed. We thought that those who left the institution against our advice showed ego strength and, therefore, were getting along fine in the community, until we took a more careful look and found out that they either returned or ended up in other social support systems, usually in the corrective system. I still remember giving a breakfast speech in Pomona, California, trying to point out to the Board of Education that special classes for the trainable mentally retarded made eminent sense because there were few classes for the educable mentally retarded and none for the trainable mentally retarded.

Special education for teachers was almost nonexistent, except for supervisory personnel. Research was mythical and mystic. I still remember that when Masland, Sarasen, and Gladwin went around the country searching out research programs, their key finding was that significant discoveries in the field of retardation were generally made by those who were not in the field and who made the discoveries accidentally.

We had a firm belief in those days that human beings had two more chromosomes than they actually have. In professional education, essentially no medical school had any kind of sequence of teaching around retardation, and the same held true in education, in psychology, and in most of the professional fields. The public philosophy was simple and straightforward: out of sight and out of mind. And that, ladies and gentlemen, was but 35 years ago.

Forces of Change

Rapidly, forces of change entered the American scene. Let me briefly enumerate a few of those, not necessarily in order of importance, but more or less in order of history: the Association for Retarded Citizens; the Parents Association; Senator Hill and Congressman Fogarty; the National Institute of Mental Health and its director, Robert Felix, who funded the Masland, Sarasen, and Gladwin study with the Parents Association; the revitalization of the EMD; the psychological educational program in Peabody College, not part of Vanderbilt; the original research program at Pacific; the Kennedy Foundation which long before President Kennedy's election, established five research laboratories. Very few scientists in those early days said with pride that their research was directed toward retardation. Obviously closest to my mind were my original collaborators at Pacific (now known as Lantermann State Hospital): Stanley W. Wright, Harvey Dingman, Robert Edgerton, Herbert Grossman, Richard Diamond, Jane Mercer, Lionel Spalding, to mention a few. Then came a quantum leap--the report of President Kennedy's panel, on which I had the priviledge of serving as vice-chair. There were some 100 recommendations. I will

select three to mention: the mental retardation research centers, the university affiliate facilities, and the creation of the National Institute of Child Health and Human Development. These are all fruits of the Kennedy panel's work, the President's Committee on Mental Retardation, which is still operational, and on which I had the priviledge to meet Ruth Diggs.

Progress to Date

Imagine the progress we have made since then. We learned that mortality is not inevitable in institutions, that morbidity is equally preventable. We learned that there are some patients who are apt to leave the institutions with higher probability than others and that community programs can, in fact, replace institutional programs. We have developed the community care system in this country in the field of mental retardation, and, as president of the American Psychiatric Association, I wish I could say that the community programs in the field of mental health work as well as they do in the field of retardation. We learned that it is imperative in the community to have a single entrance point to the system at which those in need can call, and which has as its responsibility the arrangement of care in a very complex human service system in which most providers do not know each other, do not talk to each other and certainly do not form coalitions. In *research,* in my judgment, we have made the greatest progress, and I clearly and intentionally compliment the mental retardation research centers. Just think for a moment--in genetics, we have gone from a misconception about the number of chromosomes to a capability of gene insertion or gene analysis, models of population genetics, and a host of important facts of new knowledge. In the neurosciences, we have made quantum leaps time and again, in neurochemistry; in imaging--from CAT scans to PET scans, to nuclear magnetic resonance; to computer quantified electronic recordings from the brain. We have learned what injury means to the developing brain; that the brain has great recuperative power. With just one more quantum leap, we will reach the time of potential brain tissue implantation. Just think for a moment that when I entered the field, there was no amniocentesis, there was no prenatal diagnosis, there was limited perinatology. We knew nothing about a host of exogenous toxins, such as alcohol and its relationship to mental retardation. We knew something about viruses, but we were a long way from eradicating most of the virus-produced types of mental retardation. We have come a long way. In my judgment, probably one of the slower fields to join us is neuropharmacology. As far as I know, there is still no drug or combination of drugs that can change the fundamental manifestations of mental retardation in a proven way. We know particularly little about the psychopharmacology of the developing and damaged brain.

In the field of *professional education,* we have come an enormous distance, and I will single out only one item for comment. With the

assistance of the university affiliate programs, we have evolved an entirely new concept of professional education, namely, interdisciplinary education. I do expect that the programs will be in place and will multiply, but even if that does not happen those involved in this work should be proud to follow the motto that only those who learn together can work or are apt to work effectively together.

In the *behavioral sciences,* we no longer seek deficiencies. We seek positive characteristics of the individual involved. We are but a short distance from having an entirely new approach to what we used to call the IQ. In the behavioral sciences, we must always remember that from the point of view of prevention, the work of early intervention is of a preventive and not of an ameliorative nature.

In *public philosophy,* from the single place of care outside the home, we have come a long way, to an array of programs in communities with institutions being essentially tertiary backup, locuses. But have we done everything. Did we reach our goal? My answer is no.

We are still chasing a host of beliefs I used to call superstition--a host of beliefs which are decided upon arbitarily or in smoke-filled rooms without having the necessary underpinnings, particularly of the behavioral sciences, before major programs are instituted. Mainstreaming, institutionalization, the least restrictive environment, developmental disabilities, the functional diagnostic criteria, did not come out of any research laboratories. We are still a long way from having anything but beliefs about rather important scientific questions. During my career, the assumed causation of autism and its relationship to mental retardation, has made a 360-degree turn. We thought it was parent behaviorally produced. We now think it is all organic. We are still full of so-called common sense wisdom, not necessarily scientific wisdom. Today, one of our firm beliefs is that the courts know best, better than professionals, better than parents. I remain unconvinced. We still have unresolved highly critical ethical questions, the right to live, the right to die; the wisdom, the rights and responsibilities of parents; the role of prenatal diagnosis; and the role of abortion, just to mention a few.

Williamsburg Conference

Let me now in turn comment on this conference. I first want to congratulate the Commonwealth of Virginia. I know of no other state where a similar attendance would greet your first speaker. Finally, I have found a community where my utterances of 25 years ago seem to make sense.

Let me also criticize the program, as I saw it, and I will return to this point later on. My criticism is not that there is too much emphasis on the biomedical aspects of prevention, but there is probably too little emphasis on the behavioral aspects of prevention. I am particularly glad

that two of my long-term friends, Jim Gallagher and Jane Mercer, will have the privilege of speaking to you.

Hurdles for Prevention

Now let me turn to prevention itself. Please note that in this speech, I did not start with the usual classifications of prevention--namely, primary, secondary, and tertiary. This was not an oversight on my part. I did not do so because, in a long-lasting chronic condition such as mental retardation, the three steps of prevention consistently overlap. Even in such a clearly genetic case as phenylketonuria (PKU), is the diet primary prevention? Would liver cell colonization be primary prevention, or would primary prevention be only what Josh Letherberg many years ago described as "euphenics," that is the alteration of the genotype of a carrier? The same holds for nonendemic goiter, for example. The same holds for Down's syndrome. Where does primary prevention begin and, particularly, where does it end? I have spoken about prevention now for 25 years and, except for places such as your community, relatively few advances have been made. Why is prevention so late in coming?

Let me give you some reasons:

- The first, I think, is the common human tendency of using what futurologists call future discount. If something is apt to happen 25 years from now, what is the point of worrying about it? I live in a state where you can observe future discount morning, noon, and night. All you have to ask is when the big earthquake is coming--that is what is known as future discount.

- A second force is a feeling of invulnerability. If it happens, it cannot happen to me. A third one is the absence of prior exposure: if it never happened to my relatives, it certainly will not happen to me.

- A next one is the lack of full understanding of what this tragic condition is all about. The absolutely foolish notion on the part, if I may say so, Mr. Secretary, of many legislators is that prevention always represents large add-on costs. That is not so. The overriding differences in our population's basic philosophical approach to the question of prevention are guided by beliefs, by religions, and by the imperative forces of democracy.

- Lastly, what stops the implementation of prevention programs is just plain inertia. I hope you will not leave Friday and say, "I have another conference behind me. When the next one comes up I will pull my files out, but until then it is easier to do nothing."

Let me make another comment about prevention and the hurdles it must overcome. In this nation, health is not a right. The freedom to carry guns, the freedom of the speech are rights; health is not. But worse than that, health's priorities in our democracy are set by healthy people who do not even believe that they could get sick. And when you come to mental retardation, priorities are generally set by those who really never encountered mental retardation, another dilemma that I think you ought to think about as you put together the state plan.

Another item that I hope you will pay close attention to as you think about prevention is responsibility. Whose responsibility is prevention? Is it a national responsibility? Is it a state responsibility? Is it a community responsibility? I advocate an overriding national plan for this country. I have encountered it in some other countries. I advocate that national plan because of the variability among states and because of the difficulties of demarcating communities. In the city of Los Angeles, for example, you have great difficulty identifying where community boundaries are. We have a mobile population that moves from state to state, from community to community. It is, therefore, imperative if we are to make major advances, that the Commonwealth of Virginia not only set its own plan and advocate it for other states, but also tell the federal government that the other states and territories want a plan of this nature.

Basic Strategies

What should be your basic strategy here in the prevention program? Let me comment on that very briefly. There are essentially two types of preventive programs. One requires no participation on the part of the individual whose condition is to be prevented--fluoridation, chloridation, vaccination, are examples. You can make enormous strides by legislative avenues, but a host of preventive programs are participatory programs. Participatory programs do not work unless the individual participates in them daily--contraception, safety belts, nondrinking for pregnant women, the abolishment of smoking--they are hard to legislate in this country because we are a democracy, a concept for which I give up, not ounces, but maybe even a pound of prevention. I do believe in democracy and I am fully aware of the price we pay for it. It is for that reason that I would like you to make it clear to yourself whether you are talking about a participating preventive program or a nonparticipating preventive program. And if it is participatory, please, educational programs are much better.

We have a long way to go in prevention, even though we are on the threshhold of being able to define an ideal preventive program. I wrote, some 10 years ago, of an ideal preventive program that should assure every child of being born with a healthy central nervous system, of having a set of early experiences supportive of intellectual and social growth, and of being protected from damaging physical and psychological trauma. Since no

child can escape all injurious agents, such a program must also strive to maximize a child's ability to cope. It is indeed not difficult to assess prevention programs against a simple definition of an ideal prevention program.

My last general comment about prevention is this: we have a host of excellent guidelines. You could for my money even copy some of those. One of the best comes from a lesser developed country with which I work very closely. It is known as a decalogue of prevention, the 10 basic rules, or 10 commandments. My good friend, Allen Crocker, probably will speak to you either about the "Golden 20" or the "Thoughtful 13." I think my good friend, Bob Guthrie, will speak to you about model state plans as he and his group conceived them. They are all superb, I can find no error, no oversight in them.

Two Admonitions

Now let me close in this basically, I hope, optimistic presentation, which showed you how far we have come and how far we must go, with my two admonitions. *You must never forget that additional knowledge is absolutely imperative.* There is no wisdom in slowing down the search for scientific truth. There is no way of recuperating unused time. There are many ways that momentum is lost and decades are needed to start up research programs. In that research and in our total approach to problems of mental retardation which transcend every human service discipline that I am aware of, we must no longer touch on the notion of the *old* idea of nature and nurture dichotomy. We must think clearly of nature and nurture interaction. I cannot in your one page listing find a single topic that is either resolvable purely by behavioral or purely by biomedical sciences. They interact, intersect, and I could give you examples where you transcend the demarcating lines between these two fields time and again. Even PKU is not purely biomedical. Just once compare an untreated PKU patient with an environmentally manipulated PKU patient, that is, the dietetically treated one. Just think of the undernourished pregnant teenager who has a child who is undernourished, who becomes infected, whose nutritional requirements go up, who is unstimulated, who is not schooled, and who cares not at all for his or her health. In that scenario, you cross all those lines. In the future I hope we will not return to the common belief of my early days in the nature, nuture dichotomy.

My next and final admonition: *we must start preventing in addition to talking about preventing.* Make a plan which, if implemented, will make a major impact on the incidence and prevalence of mental retardation in this commonwealth as well as in other states in this country and, since science is international, throughout the entire world. You carry a responsibility that is far beyond the task which is on the papers that were given to you. You carry the hope of mankind and you must obey, by

that obligation, to finally get the show on the road in the prevention of mental retardation.

Keynote Panel

Genetic Issues

by Godfrey P. Oakley, Jr., M.D.
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It is a pleasure to be here and see such a large group of people interested in prevention. It is quite heartwarming to see a state that is taking this issue seriously. I think the people who planned the conference have been done very, very well. My instructions were to make sure that I had some suggestions for action plans. Not pie-in-the-sky kinds of things, but things that could actually be done. So I suppose my comments this afternoon might be divided into two groups: the first group is some of those pie-in-the-sky, general kinds of comments, and then we will wind up with some rather specific things that should be considered when looking at an action plan for genetics.

If we could have the first overhead, please. This is a rather simple concept, that there are many genetic diseases that cause mental retardation. There are more than you can count on several hands, and I am sure that over the last 35 years, Dr. Tarjan has seen many come to pass, and I am sure over the next 30 years, we will identify more, particularly if we keep the research up. If we could have the next overhead.

Preventing Genetic Diseases

It very simply says that genetic diseases can be prevented. The reason I make that point is that I know that there are some perinatologists in the audience, and one of the things that I like to point out to perinatologists is that when they do their perinatal statistics they often take the numbers of severely malformed babies and put them as a footnote in the table and do not consider them when they are looking at the infant mortality or perinatal mortality. I think it is important to put those numbers back up on the table, because many of them are caused by genetic conditions, and many are caused by environmental conditions, and many are associated with developmental disabilities that can be prevented, if not today, then we certainly ought to strive to learn to prevent them tomorrow. It is another case of making sure we do not say, "Out of sight, out of mind." Next please.

The next statement-- there are many different strategies to prevent genetic diseases and their effects. We heard a very nice rendition of that from the keynote speaker, who outlined a progression of kinds of formats in which one might prevent diseases, but I think that we, perhaps, forget that genetic diseases can have more than one intervention strategy. If we could look at the next overhead, I used Down's syndrome as an example of a disease for which there can be many different intervention strategies.

Many of you who know me know that I am really an epidemiologist and not a geneticist, and I am interested in why babies have environmentally caused birth defects and mental retardation, so you will have to put up with my reminding you that although Down's syndrome is associated with an extra chromosome, we do not have the foggiest notion of what the environmental factors are that cause that to happen. If we knew what they were and how to remove them, then we might actually do some of that primary prevention that Dr. Tarjan talked about. I think we need to think research.

Decreased Prevalence of Down's Syndrome

Between 1960 and 1974, I think one of the least recognized and unheralded prevention actions happened in this country and actually around most of the western world. Between those years, the prevalence of Down's syndrome, the most common known cause of major mental retardation, went down by 25 percent. That is an incredible achievement. It is even more incredible because nobody stands up and takes credit for it. As far as I am aware, nobody has received the Nobel Prize for it. It derives very simply from the fact that women in this country changed the pattern in which they have babies. They have fewer of them and they have fewer of them over the age of 35. For example, in 1960 roughly 11 percent of all babies were born to women 35 and older. In recent years, that number is around about five percent. Concomitant with that change was a change in the proportion of Down's syndrome infants that were born to women over 35. In 1960, that was approximately 45 percent; in the 1970s that number is down into the low 20 percents.

I remember several years ago when a parents' organization called us because it had this very unusual observation; almost all the parents in the local chapter of the Down's syndrome group were below 30. They thought there might be some environmental cause there, but when we started to look a little closer it was exactly what one would expect in the 1970s when the pattern had changed.

It is worth pointing out, I think, when one looks on an international basis, that there are some countries where the incidence of Down's syndrome is roughly twice what it is in the United States simply because that shift in maternal age distribution has not occurred. For example, in

Spain, Italy, and Ireland, the crude rate of Down's syndrome is roughly twice what it is in the United States. If you go to China where only two percent of all babies are born to women over 35, they have even improved more than we have on this particular issue.

A second approach to Down's syndrome is prenatal diagnosis. We first started this with women who had a positive family history, and now we have rapidly moved to offering it to women considered to be at advanced maternal age. If you look very carefully, there are some women who might use amniocentesis if they knew more about it. One of the things we learned in looking at who uses amnioscentesis is that people who live in cities tend to use it more than people who live in the country and certainly in the rural south.

Dr. Kelly, or I guess it was in the material that came to us, suggested that about 25 percent of the women over 35 years old in Virginia actually have prenatal diagnosis. Why have not the other 75 percent had prenatal diagnosis? Did they not have it because they were informed about it and did not want it, or are there still substantial numbers of women who simply are uninformed? Could we have the next overhead?

Dramatic Decrease in Rh Disease

This concerns Rhesus hemolytic (Rh) disease and, again, the point is that here is a single gene disease that has gone, in my lifetime, from a cause-unknown case, to various and sundry intervention procedures, to an almost completely preventable disease. In 1940, we knew that babies and children had kernicterus and mental retardation, but we did not understand the basic underlying mechanism. In the early 1940s, the blood incompatability that was the cause of this problem was understood. That led to the first line of therapy which was an exchange transfusion. That solved some of the problems. It solved the problems of children who were born alive who might have become mentally retarded with kernicterus if they had not received a transfusion. That still left a considerable burden from spontaneous abortions or late deaths in utero due to the anemia associated with this condition. In the early, or mid-1960s, in utero therapy was developed and that led to more babies being born who would have died in utero with this condition. But what is the nicest line on this diagram is the fact that, in the late 1960s, a vaccine was developed which, through research, was shown to be more than 90 percent effective so that the incidence of Rh disease in this country has dramatically gone downhill. In 1970, there were roughly 1,000 babies who died from Rh disease in this country; in the past year that number was between 150 and 200 deaths.

An obvious question is, if this prevention works so well, why have not all the deaths disappeared? One reason--there were some women who were sensitized before the vaccine came about, but also there are still

some women who need this prevention service who are not getting it. So that is a question to consider in Virginia as you put your action plan together. May I have the slides now and turn off the overhead.

Causes of MR Today

I would like to put back on my epidemiologist's hat. At any rate, the point of this slide is that in knowing the causes of mental retardation in this country today, we are not in very good shape. We wind up having to use data that are 20 to 25 years old. These are data from Quebec, drawn from a population of children who were alive in 1968. You can see that if you look at the causes, Down's syndrome was the leading known cause of mental retardation at 23 percent; single gene diseases accounted for 21 percent; diseases that had their onset later than three months accounted for 8 to 11 percent; birth injury accounted for 1 percent; low birthweight accounted for 3 percent; perinatal damage 6 to 9 percent; and here, hypobitarheubinemia 1 to 2 percent; and, again, this large 33 percent was unknown.

Now the obvious question is what are these percentages today? The next slide shows some specific causes from that same study, and I think it is worthy to see these when you start thinking where the impact can come in terms of prevention. Again, this was before PKU screening and treatment and tubercular meningitis, before measles eradication, pertussis, and pertussis immunization. Again, it would help us to know what the causes are so that we know where to direct programs. The next slide is, as far as I am aware, the most recent large body of data in the United States, and this comes from the collaborative perinatal study. These were children who were born between 1959 and 1965, and if my recollection is right, some of these babies were born in Richmond. And again, here we have an indication of at least some of the causes that came from that study.

Down's syndrome accounted for roughly 16 percent of the total; with severe MR due to hyopthyroidism, 1 percent; lead poisoning, 1 percent--and as Dr. Broman presented at a recent conference--some more numbers would suggest that maybe as many as 30 percent were unknown; post neonatal trauma, 1 to 2 percent. But again these data are outdated. We have neonatal intensive care nurseries. We have all the many things that have occurred since 1965 that work to prevent mental retardation. The point that I would like to make here is that it is very hard to plan programs, and it is hard to evaluate programs if you do not know where you are and you cannot monitor as the days go by.

MR Scorecard Needed

This is a plea for a scorecard, and by that I mean, what is the incidence of mental retardation in Virginia? Today, 1983? What are the causes of mental retardation in Virginia? Are cases of preventable MR occurring? What needs to be done to improve prevention? I would make an editorial comment while discussing the scorecard. It is not possible, and I repeat, it is not possible to do a good job with a scorecard if you are not able to know on an individual basis the patients who have the diseases you are concerned with. You cannot do some crude count without referral to identities, because patients show up in more than one institution or more than one health care delivery system. You have to have personally identifiable data. Now that carries with it a major responsibility. When you have a registry of people with developmental disabilities, it is very important to devise mechanisms that protect those people.

We have had some experience in Georgia with the birth defects registry. We have now, since 1968, registered some 15,000 babies who have had severe birth defects. We have interviewed roughly 1,500 of the mothers of those children, and we find that although we have those names in the register, we are unaware of any detriment that has occurred to those families because of that register. In fact, we find that the average patient who has a child with a birth defect has seen so many doctors, or so many doctors in rapid succession, that she is really very willing to sit down with our interviewer and try to give all the genetic and environmental history, and it is quite a worthwhile, useful thing. We almost never are turned down by the parent.

Two Approaches to Prevention

One might say that there are two broad approaches to prevention. One is based on *screening*, and usually when a screening methodology is used, you are dealing with large numbers of people at low risk. The purpose of the screening is to identify from the low-risk group those that have a high enough risk so that other testing and treatment can be done. One usually finds that when one is screening, one is going at a large proportion of the population and that usually, but not always, one finds the majority with a disease.

Another approach is to deal with the *high-risk population*. Here, the numbers of people that need to be tested are relatively small, for example, the families that still have children in institutions. If you were to consider that population, there are a relatively small number of high-risk people who need to be investigated and to have genetic counseling. These people, by virtue of already having a child with a problem, would be known to be at a high rate of risk. On the other hand, this approach usually accounts for a small proportion of that particular kind of disease.

The next overhead gives us an example. I am sure you will hear, and we will discuss tomorrow in the genetics group, neural tube defects. By neural tube defects, I mean primarily anencephalia and spina bifida. Anencephalia is the incomplete development of the brain and head and is always associated with in utero death or death in the early days or weeks of life. Spina bifida, on the other hand, is primarily a physical disability, although there is an increased risk among spina bifida patients of MR. This appears to have lessened in the last decade when care has improved.

In the high-risk situation, we have families that have previously had a child with a neural tube defect (NTD). Their chance in a subsequent pregnancy of having a child with a similar condition is on the order of 2 percent in this country. You may be familiar with textbook rates of 5 percent, but they come from the United Kingdom, where the rate is higher than it is in this country. I have made a guess here that of the Virginia women who have a child with an NTD in a given year, only 2 to 3 percent of them will be women who previously had an affected child. So that if one has a genetics counseling program or an amniocentesis program directed at only high-risk women, the maximum impact is only on three of the cases that occur in Virginia every year.

Women who have previously had children with an NTD would birth a total of some 150 babies a year, so that one has to offer amniocentesis and counseling to roughly 150 women a year to get at these three cases in this high-risk situation.

One might contrast that in the low-risk situation. (I said there were roughly 75,000 births in Virginia annually, but someone said earlier there were 78,000; I apologize.) To offer maternal serum or alpha fetal protein screening would be to offer this procedure to a large number of women, but in fact it would be directed at roughly 112 cases of NTD a year. This particular screening would pick up about 75 percent, or in this case, 84 cases. Again, I use just as an example of the two approaches. And I think that when you are considering either the screening or high-risk approach and balancing off the pluses and minuses, it is nice to keep some of those concepts.

So to summarize my points:

1. Let us get a scorecard--define the problem of mental retardation in Virginia and evaluate in an on-going way the effectiveness of prevention efforts that now exist.

2. Provide high quality neonatal screening, diagnostic testing, and treatment. I think from things I have read that this is going on to a great degree in this state already, but Virginia, like other states, is concerned with what happens to maternal PKU, and it needs to be a part of trying to figure out how to solve that problem.

3. Provide genetic counseling and diagnostic services to high-risk families with MR or DD children and infants with NTD and others.

4. Provide quality genetic counseling and diagnostic services to women 35 and older who are informed about the procedures and who want these services.

5. Ensure that all Virginia women who desire it have access to high quality maternal serra, alpha fetal protein screening to screen for NTD. I mention the NTD issue because this is a slide that shows on a map the incidence of open spina bifida throughout the United States as we could best piece it together. You might notice that the highest rates are in the Southeastern U.S. and the lowest rates tend to be in the West. Virginia happens to be in the group with the highest rates of NTD in the country; it is a good place to consider screening. Also, it is good to ask why are the rates high? And what environmental and/or genetic factors account for that?

As you probably know, the FDA is in the process of making it possible for companies to sell reagents to do the alpha fetal protein testing, and the testing is likely to become a part of medical practice relatively soon. If you will look at (2), at this level, a black woman in Atlanta and a black woman in Richmond would have roughly a one-in-200 chance of having a child with an NTD, whereas a white Richmond woman would have a roughly one-in-45 chance. That is roughly a four-fold difference. Interpreting this test needs to be done carefully. I think anything that this action plan can do to increase the likelihood of high quality laboratory services and high quality interpretation of those services, so that the patient understands what it means, would be quite good.

6. Assure access to Rh immune globulin. Connecticut, for example, has a nurse whose job it is to travel the state of Connecticut and investigate whether there are unnecessary cases of Rh disease occurring, and whether women who should be getting the vaccine are not getting it. That is an approach that does not cost very much money and could be considered in Virginia.

7. And finally, assure access to a Tay-Sachs screening program.

I'm sure that there will be other recommendations that will be developed but these are places to begin.

Keynote Panel

The Impact of Intervention on High-Risk Children

by James J. Gallagher, Ph.D.
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Early childhood, that period roughly from 18 to 60 months, has received substantial attention in the last two decades as a period of special vulnerability for the possible development of mild mental retardation. During that period, language emerges and develops, social adaptation patterns begin and solidify, the potential adult begins to be revealed. It is for these reasons that a diversity of attempts have been made to intervene in a postive fashion in order to prevent or reduce intellectual subnormality and social maladaptation, especially with those children seen to be at risk. It should not escape our attention, however, that there are also physical threats to the child during this developmental period.

Biological Insults

Once children have successfully passed through the perinatal and infancy stages, many persons believe that they are now relatively free of physical threats that might result in mental retardation. Unfortunately, that assumption is not entirely correct. There are four dimensions that should be mentioned briefly here: lead toxicity, malnutrition, accidental injury, and inflicted injury.

Lead. The clinical effects of lead poisioning through ingestion of paint containing lead, lead from gasoline exhausts, and some food and beverages are well known. The effects of lead toxicity on the central nervous system may cause irreversable brain damage. In addition, there appears to be an interaction between nutrition and the susceptibility of children to the negative effects of lead ingestion. When dietary intake of iron is low and borderline iron deficiency anemia is present, the absorption of lead from the gastrointestinal tract is greatly elevated. A. Huber, in *Handbook of Mental Retardation,* 1983, points out that similar effects occur when calcium intake in children is low. This also enhances lead absorption. Whether undernutrition is a serious factor in the creation of mental retardation by itself is still a debatable issue,

but its role in sensitizing the youngster to a greater risk for lead toxicity seems well-documented.

Nutrition. The role of malnutrition in the creation of mental retardation is still being debated. There does seem to be increasing acceptance of the potential negative effect of serious malnutrition on children's intellectual development. It remains difficult to sort out the effect of malnutrition from many other negative environmental factors that one usually finds in the same situation. H. Ricciuti, in a recent review in the *Journal of the American Dietetic Association,* concluded that it is still impossible to separate malnutrition from concomitant negative social factors that often exist in the same setting.

H. Martin (*Handbook of Minimal Brain Dysfunctions,* 1983), reviewing animal studies on the effect of adequate diet, comments: "There seems no question that protein and calorie deficiency during periods of most rapid brain growth result in permanent changes in brain composition, probably in brain function," and he concludes, "The presence of early protein and calorie deficiency has played out in depressed intelligence and learning in a way that seemed etiological."

Accidental injury. J. Chisholm, in *The Biologic Bases of Pediatric Principle,* 1968, has pointed out that accidents still represent the greatest cause of death in all children over 1 year of age. L. Margolis and C. Runyon noted that motor vehicle crashes are the leading cause of childhood fatalities, accounting for over 4,400 deaths in 1978. In addition, children involved in auto crashes are more likely than adults to sustain injuries. Although it is uncertain how many of these injuries translate into mental retardation, it certainly is a significant factor that needs further clear-cut demographic documentation.

Intentional injuries. The final dimension of physical cause of mental retardation involves child abuse. The recognition of the role of child abuse in creating children with head trauma and possible mental retardation or developmental disabilities has been noted, but the specific numbers are difficult to project. In *Concerning Child Abuse,* R. Keith estimated that child abuse may account for 6 percent of new cases of cerebral palsy annually and 25 percent of new cases of serious mental deficiency. In addition, Martin suggested that nutritional deficits are present in at least 30 percent of diagnosed child abuse cases.

In all of these conditions, the preferred treatment and public policy emphasis would seem to fall in the public health domain rather than in the support of specific clinical intervention. Public policy that limits the use of lead in paint or in gasoline, that provides minimal nutritional requirements to young children, that mandates the use of seat belts in automobiles for young children, and that reduces the sociopathological

conditions that spawn child abuse, could all have a significant role in the reduction of mental retardation from physical causes in early childhood.

Psychosocial Insults

For more than two decades, we have been pursuing the impact of early child intervention for children who are developmentally delayed. There has been some disagreement as to the actual prevalence of mental retardation or developmental disabilities. George Tarjan and J. Mercer have both suggested that about 1 percent or less is an appropriate figure, much less than earlier estimates. Regardless of the actual figure, the vast majority of children currently identified as mentally retarded fit the *mild* category. Therefore, any success in prevention of early retardation could have enormous public policy impact. A generation of research has yielded somewhat less than was hoped for, principally because we have been concerned with a description of the end product of the intervention, and have too often overlooked the mechanisms or interactive processes by which we could explain what was happening.

If there is one problem that has been generated by the social scientists themselves during that era, it has been the creation of overexpectations in the general public. I recall rather vividly a personal incident when Head Start was under serious attack for being a failure. I confronted a young, bright White House aide who was loudly proclaiming the failure of Head Start with a question, "What did you expect Head Start to do which now causes you to label it a failure?" He said he expected that these youngsters would be above average by the time they went into school. This lawyer can be excused for his optimism. We, in the social sciences, did little to dissuade him, or those like him. If they wished to believe that we were miracle workers or could solve major social issues, we were content to let them do it. Our unrealistic aspirations could be compared with the description of Garrison Keeler (from National Public Radio's "Prairie Home Companion") of that mythical Minnesota town of Lake Woebegone where "all the women are strong, all the men are good looking, and all the children are above average."

Two crucial questions confront us. "How malleable or changeable are young children in their cognitive or social development, given improved circumstances?" and "What are the mechanisms--social, genetic, psychological--that result in intellectual subnormality?" Sometimes fiction helps remind us of our boundary lines. The science fantasy book, *Flowers for Algernon,* later turned into a movie called "Charlie," portrays a mentally retarded young man who takes a special drug and becomes the most gifted individual in the world. Then, as the effect of the drug wears off, he slowly returns to his mentally retarded state. This is science fantasy because there is no way we can conceptualize anything like that happening as the result of our "treatments" today.

Similarly, when we look at a 3-year-old mute autistic child, we do not expect him, after treatment, to become the president of his high school class or chairman of the local chamber of commerce or a TV master of ceremonies. It would be well for us to state as clearly as we can where the outer boundary lines of malleability are in cognition and social processes.

We certainly have demonstrated that we can make a significant difference in early cognitive development, and that significant difference is probably between one half to one standard deviation on a standard intelligence test. We can increase social skills and reduce more obnoxious patterns of behavior.

The work of many researchers who have conducted retrospective studies of the characteristics of children with mild mental retardation has led to a number of incorrect or oversimplified assumptions or conclusions. The strategy was simple, as it turns out, much too simple. It was to find a group of mentally retarded individuals and match them on life age or mental age scores with a group of average children, and then see what differences can be found. These differences could then be assembled into a high-risk index or used to portray the distinctive features presumably leading to mental retardation. With such a strategy, we found mild mental retardation was linked to poverty, family and social disorganization, limited intellectual stimulation in the home, etc.

If only we could compensate, we thought, for those early deficiencies, we could then perhaps prevent much mild mental retardation. A generation of intervention studies was carried out with the treatment being general intellectual and social stimulation provided to children presumed to be at high risk because of the presence of these characteristics.

What is risk? What has now become clear from prospective research studies, is that many, indeed most, children growing up in poverty with these presumed "high-risk" factors do *not* become intellectually subnormal to the degree to which we would call them mentally retarded. There appears to be a subset of factors within this larger group, with some presumed additional dynamics operating, to create the child who is at special risk for mild mental retardation.

C.T. Ramey and J.R. Brownley tried to seek a better answer to the risk question. They studied 52 "high-risk" families involved in a longitudinal intervention program with the goal to derive a predictor set of variables that would distinguish between families where the children were within one standard deviation of the mean of average ability from families whose child fell below that point. The predictors which characterize more normal cognitive development included more democratic child-rearing attitudes on the part of the mother, positive child temperment characteristics, and less time spent by the child outside the

home in the first year being care for by others. Such factors at least could be translated into some reasonable suggestion of possible mechanisms. For example, we know that low-income mothers seem to demonstrate an increasing tendency not to interact with an irritable child. Such a limitation would contribute to an already deprived linguistic environment and cause children of irritable temperament to be at a particularly high level of developmental risk as pointed by Ramey and Brownlee.

Plasticity. One key study that provides some potential guidelines on the plasticity of intelligence is the follow-up review organized by I. Lazar and R. Darlington. Twelve investigators who had carried out intervention programs with infant and preschool personnel agreed to participate in a follow-up study. This study revealed that the children who have been in these programs surpassed their control subjects on IQ tests several years after the program had ended (but there were no difference at follow-up), were less likely to need special education services, more academically efficient, and had better self-images. Nevertheless, the average IQ score at follow-up time of the treated child was still one standard deviation below national norms, suggesting that a .5 to one standard deviation gain in cognitive performance would be about as much as could be expected through this stimulation type of program.

There is one outstanding exception to that pattern. The Milwaukee Project, reported by H. Garber and R. Heber, in *Psychosocial Influences in Retarded Performance,* 198[illegible], selected families from the lowest economic census tract in Milwaukee and choose children of mothers scoring under 80 IQ as their high-risk group. They have reported extraordinary success from a combined child stimulation, mother-training program beginning in infancy. Four years after entering school, the experimental group still had a mean Binet IQ of 105 compared to a control mean of 85 IQ points. In the social adaptive area, one-third of the experimental subjects were still reported to be having social or behavioral difficulties in school, however.

Another prospective study, the Abecedarian project, by C. Ramey and R. Haskins, 1981, that provided a stimulation program beginning shortly after birth, obtained a result more in line with the other findings, a gain of .5 to one standard deviations for the experimental group on measures of cognitive growth.

Even more intriguing is that for both the Milwaukee and the Abecedarian project very few of the children from either experimental or control group were measured -2 standard deviations below the mean, the traditional boundary line for significant intellectual retardation, despite their supposed high-risk status.

The malleability of moderate and severely handicapped preschool children is more difficult to assess. Central nervous system damage

always requires conservatism. The intervention programs designed to help such children are highly individual in order to match the unique combination of problems that such youngsters present. There is no single "treatment" as such to be evaulated, but only combinations of treatments. Such programs have been assessed as positive by the evidence of children reaching developmental milestones earlier than expected, the effective integration of handicapped and nonhandicapped children, and the lesser need for special education services when the child reaches school age.

Mechanisms of Intellectual Development

As troublesome as the question of malleability, the more difficult issue is the discovery of those forces that create the conditions of risk. In a recent review of research progress and objectives of mental retardation for National Institute of Childhood Diseases (NICHHD), D. Purpura, J. Gallagher, and T. Tjossem, 1983, stated:

> What must be addressed now is the fundamental question of mechanism at the cellular, neurointegrative and sociobehavioral levels of organization. . . (p. VI-3)

and further added:

> . . . Knowledge is needed from every branch of science in order to understand the interaction of these elements and the development and behavior of children and adults. (p. VI-1)

In *American Psychologist,* 1982, G. Albee presents a model of psychopathology that reflects the current view of the blend of organic and social factors.

$$\text{Incidence} = \frac{\text{Organic Factors} + \text{Stress}}{\text{Coping Skills} + \text{Self-Esteem} + \text{Social/Maternal Resource}}$$

In such a formula the conditions in which individuals operate become critical to their adaptation. Furthermore there are inevitable interactions within the forumla itself. The more the individual possesses coping skills, the less effect stress will have. The more success the person has, the less powerful will be the organic factors in creating a psychopathological condition. Reviews by A.J. Sameroff and M.J. Chandler, 1975, and specific articles by P.S. Zeskind and C.T. Ramey, 1981, point out that the combination of malnutrition or other physical problems with poverty creates more serious developmental consequences than would the same problems in the middle-class family.

Renewed efforts to conceptualize models of intelligent behavior are appearing, stimulated in no small measures by interests in mental retardation (Sternberg, in press). The information processing paradigm represents one major approach to study specific processes of memory, attention, and components such as metacognition (i.e., E.C. Butterfield and J.M. Belmont, 1977; J. Campione and A. Brown, 1978). Interest in the *executive function,* the decision making function of the intellect, has increased. Gallagher (in press) has pointed out four types of decisions assigned to that function.

1. The executive function inhibits immediate or random response to stimulus pending further mental activity.

2. The executive function chooses which stimuli in the environment to attend to.

3. It chooses which strategy from the individual's repertoire to apply to a given problem situation, whether a multiplication problem or an angry parent.

4. It chooses the mode of response to confrontation, for example, from talking, to running, to fighting.

Few of these information processing models have taken on the even more complex problem of the developmental aspect of intelligence. It is that realization that has led some investigators such as Ramey and McPhee (in press) into a systems approach to try to capture some of the many complexities and interactions noted.

As Ramey and McPhee point out:

> The overriding conclusion must be that a complex process like development demands a multivariant, multilevel, and frequently interdisciplinary approach. It is worth repeating that behavior is a product of the entire system. Components studied in isolation may yield some information about processes, but behavior cannot be explained by the action of isolated parts.

It is the need to pursue these complex interactions and mechanisms that has guided a number of the studies on the longitudinal intervention program now at its 12th year at the Frank Porter Graham Center at the University of North Carolina at Chapel Hill.

This program of research identified children at high risk for mental retardation. These families were randomly separated into one group that obtained an eight -hour daycare program designed for stimulation and another group who received some nutritional supplements and health care by no stimulation program. Some of the interaction studies are briefly noted here:

- A free play setting was established and reciprocity in social interactions between mothers and their 3-year-old children was assessed in 51 mother-child dyads.

- Low-income mothers tended to remain less involved with their children in interaction than did middle-income mothers. The children of low income mothers spent more time in nondirected play.

- A comparision of parent-child communication efforts in the same free play setting at 20 months revealed that low-income mothers of the experimental group communicated more with their children than did low-income mothers of the control group, but both communicated less with their children than did middle-income mothers with their children.

- In relating mother-infant interaction and maternal behavior and attitudes to IQ scores at 36 months, we found that maternal IQ was a key factor in the children in the control group, but not in children in the experimental group.

- Democratic attitudes and level of mother-child interactions predicted the IQ scores of children in the experimental group, but not in the children in the control group.

All of these findings suggest that there are continuing processes going on in daily transactions in the family and in the environment that are shaping the eventual developmental product in a complex model of systems interactions.

Policy Recommendations

The recommendations that follow from this discussion of sociobehavior factors do not follow the same neat style reported earlier that suggested seat belts to prevent child accidents or eliminating lead from house paint and gasoline. Nevertheless, the encouragement of a healthy social environment which reduces the probabilities that a child will be neglected or abused, which increases the probabilities of parent-child linquistic interaction, that encourages a belief that one has some control over his/her environment, has much to commend it. This would appear to reduce the probability of mild mental retardation.

It has been said that a recommendation for the amelioration of mental retardation would have popularity in inverse proportion to the number of people that the treatment affected. If we could devise a "smart" pill (i.e., megavitamin) that children under threat of mental retardation could take that would help them become competent, how joyful a circumstance!

How honored would be the pill creator! Clinical solutions are always popular.

If, instead, the solution to mild mental retardation requires a change in our own social habits and attitudes or, even more distressing, a reallocation of societal resources that might affect us all, then we may in fact expect limited enthusiasm for such solutions. It is the unenviable position of the social scientists that they must present a "public health solution" that would call for social reform, the systematic dimunition of the conditions of poverty, and the reduction of social discrimination. The call for more research reflects the need to discover the precise developmental mechanisms of mild mental retardation.

The additional research needed here clearly should reflect the complexities noted in this paper. If we are to puzzle out these complex developmental threads, we must observe children and families over time and across a number of biological, social, and cognitive domains. Until we do, the promising arena of early childhood will still contain many important mysteries; predominant among them would be how mild mental retardation progressively unfolds.

Keynote Panel

Perinatal Issues

by Gordon B. Avery, M.D., Ph.D.
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It is heartwarming for me to know that we all, though we come from different disciplines, care intensely about children. During the coffeebreak I met my old friend, Hugo Moser, who is our after-dinner speaker for tonight, and he asked me, "Well, how is it going with the little babies?" And I thought to myself, well, maybe I will take the next 30 minutes to try to answer Hugo's question because I am now in my third decade of working with the little babies. I am a neonatologist, which means that I do hospital-based intensive care of newborns, and I would say, by way of giving you the overview quickly, that in the first decade we were working for survival of prematures, and, in the second, respiratory things were the focus of our discipline. In the next decade, we moved to a focus on nutritional and metabolic support, and I think this may have, in fact, contributed to the improved quality of our survivors because we have extra uterine fetuses--some for nearly their entire last trimester--in our nurseries with rapidly growing and changing central nervous systems, and, of course, they require exquisite metabolic and nutritional support to grow normally and optimally. I believe that in neonatology, this is the decade of intensive care of the brain. We are just learning how to do it. We have new devices like ultrasound machines that we can wheel to the bedside without disturbing a small premature on a respirator. And we can learn about the physiology and corlets of hemorrhage into the brain, things that were impenetrable except at the autopsy table after they no longer were relevant. And we are searching for other ways of taking care of the brain with the same kind of efficiency as we learned to take care of the nutrition, the temperature, the respiratory needs of these sick babies. I might quarrel with Dr. Oakley's incidence figures because it looked as if something less than one percent of the children with developmental defects or mental retardation was made up by former prematures. But even the collaborative studies are almost 20 years old, and neonatology has changed so fast that our current ability to bring through to survival babies weighing less than 1,000 grams is less than 5 years old. So that if you are going to ask, how about today's babies, how about last year's babies, you either have to have an answer that is bad because it is a short-range answer, or you have longer

term studies on babies cared for 10 years ago with very, very different techniques than we now have to give optimal outcome and support.

Nevertheless, I am going back and giving you an overview of this very dynamic and changing field in which I live and work with a sort of good news, bad news, unfinished agenda-type of annotations along the way.

Early Care of Newborns

This slide comes from a period in which it was customary to regard the premature human infant as a sideshow freak. Actually, Martin Coney succeeded in keeping some human babies alive in incubators that were modeled on the chick hatchery technology, and he found that they could be exhibited and people would pay 25 cents to see human babies--prematures surviving in incubators. At the St. Louis Exposition in 1908, this building was there for that purpose--it says "Baby Incubators" on the building--and there are the incubators, here are the paying customers coming by, a nurse, Coney himself, and it really was considered very curious. A few of the babies occasionally survived, but their families had long since given them up and they generally had to be placed in foundling homes because nobody wanted them.

This is a scene from our nursery. I now recognize that it is out of date by some of the pieces of equipment, but you see there is some change in style. There is a respirator, an oxygen blender, three or four intravenous pumps, an overhead radiant warmer, a servo control unit, equipment for resuscitation, and if you look very closely, down in the corner, you can see the baby. This is the way it is today.

These are outcome data from the University of Colorado in Denver, for survival for the period 1958 through 1969. Notice that the optimal survival, with less than .2 percent mortality, occurs at term gestation and appropriate weight for dates. This is the normal curve of a baby through the last fetal weeks, 24 weeks, at term and post term. Babies too large or too small or too early had a high mortality, and it was basically 85 percent in this smallest group. Remember the color scheme, remember how the slide is set up, because the next one will be from the same center, just a few years later.

Notice how the territory of the high mortality has retreated down to the smallest babies. Notice how the territory of the best survival has increased and there is no argument, I think, that mortality has dramatically improved under the auspices of perinatal intensive care as it has now developed.

There used to be a disease when I started first to work in nurseries called Little's disease. It affected something like 60 percent of babies

weighing less than 1,500 grams or less than 3.5 pounds birthweight. It was thought to be a disease of prematurity itself, and the suggestion was that being born early, by itself, conferred inferior outcome, especially spastic diplegia. I thought that it was called Little's disease because the babies were little. In fact, it was called Little's disease because it was described by Dr. Little, an obstetrician, in 1862. He noticed that babies with rigidity confined to the legs were usually preterm and only seldom had birth trauma, whereas other patterns of cerebral palsy (CP) were found in primarily term babies virtually all having perinatal trauma. He, therefore, called attention to this phenomenon. We now know how to care for babies with Little's disease, and part of the happy news is that the incidence of spastic diplegia in former prematures has dropped from 60 percent to as little to 5 to 10 percent in a series.

Low Birthweight Babies

This is some of the bad old news; I am not sure how well you can see in the back, but it is a composite of multiple studies from different laboratories and even different countries--all in babies whose birthweight was less than 1,500 grams (3.5 pounds)--and deals with the IQ at follow-up, major central nervous system (CNS) defects, retrolental fibroplasia (RLF), seizure disorders, and so forth. The news was rather bad in that an IQ of less than 90 was occurring in something like half of these babies, but the dates of their birth all place them before the era of modern perinatal intensive care, before 1970.

This is data from a single center, the University of California, San Francisco--all babies less than 1,500 grams. Again I keep using this particular figure because it is where the slope becomes steeper and it allows some comparison between studies. For the years 1965-1974, notice that the mortality rate has come down and basically dropped in half, also that the level of IQ during these same years was gradually climbing. This is important data because at times I find that my tribe and I are praised because we are saving these babies and at other times are cursed because we are bringing through damaged survivors who would otherwise have perished shortly after birth without this elaborate technology. I believe there is a presumption--and it is only a presumption, it does not rest on hard current data--that the same things we are doing to make the babies live also contribute to improved quality of life in the survivorship.

This is data from Hammersmith Hospital in England, and the comparison is for IQ on survivorship with one of the parents. The thought in this study was that there are, other than prematurity itself, factors in the outcome and that perhaps some of them were controlled by the family environment--similar genetic stock, similar lifestyle, and so forth--and so parents in this case were compared with children. The children are in the top, the parents are on the bottom; the shape of the histogram is not

greatly different. The implication is that it is not such a hopeless thing to be born a premature.

This is a slide that is a little loose scientifically because it compares eight or nine different studies and uses somewhat different criteria. It was given to me by Mike Simmons, and I show it because I think it makes a point that would take an extensive review of data to make in any other way. On the horizontal axis is time--1945 through 1975; on the vertical axis is percent of normal survivors--all looking at babies in this very low birthweight group, under 3.5 pounds. Notice that there is a general upward trend with time so that as more recent time approaches, the proportion of intact survivors has improved. I think you cannot take this too literally because each study used different follow-up intervals, different criteria of normalcy and, if you factor in the now-increased survival of babies under 1,000 grams and even under 750 grams, there are clearly damaged survivors among those babies. But I think it supports the generality that what is good in the care of vulnerable babies is good for their survivorship--their quality of life--as well as for their survival.

Unresolved Problems

Now, that was the good news. The bad news is that there are residual problems that we have not licked. One of them is RLF. There was a time in which this was believed to be oxygen toxicity, pure and simple. There was an epidemic in the late 1940s and early '50s when oxygen was believed to be non-specifically good for prematures, and it was a leading cause of blindness during that time. With more conservative use of oxygen, RLF receeded somewhat into the background. However, it turns out that another powerful fact of vulnerability is immature birth. And now that large numbers of babies under 32 weeks gestational age are surviving, we again see from excellent leading medical centers using regularly controlled blood oxygen levels that about 8 to 12 percent of very low birthweight babies have some degree of RLF. Now, notice on this slide that if you grade the severity of this process, it is the advanced grades that lead to blindness and lasting damage to the eye; the majority of grade 1 cases regress without any apparent aftereffects. Most of the cases are of the mild type, but every substantial center that cares for a goodly number of small premature infants will discharge, in the course of a year, some babies affected by this problem, some of whom will be blind.

This is a tabulation we did, 1979, 1980, of 43 babies weighing less than 1,000 grams; and it is presented to show that it is not a bowl of cherries to be born at that weight. Seventy-nine percent of them had severe pulmonary disease; 51 percent had spells in which they stopped breathing and required medication or resuscitation; 66 percent had some degree of ventricular hemorrhage; 21 percent had evidence of blood-born infection; 12 percent had colistatic jaundice, that is jaundice probably associated with their intravenous feedings; 9 percent had necrotizing

endocolitis, a condition in which there may be damage to the lining layer of the gut, sometimes even requiring surgery; 7 percent in this particular series had retrolental fibroplasia; and about half of that particular cohort survived.

If one looks at the intraventricular hemorrhage, it appears that about 66 percent of it is of the minor grades of severity and the remaining 33 percent of the more advanced grades. In our follow-up clinic, we have found that this ventricular hemorrhage, though very striking, is a poor predictor of long-range outcome, and we have seen very good quality neurological and developmental outcome in babies with grades 1 and 2 hemorrhage.

This is another of the unsolved problems, the cumulative effect of perinatal insult and then some degree of deprivation or lack of rehabilitative environment after discharge from the nursery.

This is a study from England where they were bold enough to talk research outcome by social class. The two you wanted to be in are the well-to-do, the middle class; the so-called working and indigent classes are here [referring to slide]. A group of babies at similar risk were discharged and followed and were found with mean IQs descending in this way, with the wide scatter meaning that individuals in all three groups were even superior, but that there was a clear double jeopardy for those with perinatal insult and lack of a rehabilitating environment.

There is other data to support the same months contention. This next slide is a group of babies who were followed; ages seven, 15, 28, 34, and 40 months, and 6 years; the chart is also broken down by socioeconomic quartiles, one, two, three, and four. What is being displayed is developmental quotients. Notice that in the highest socioeconomic quartile, the top 25 percent, the scores held up through to school age, and in the bottom quartile, they deteriorated essentially through preschool childhood.

This is data from Pam Fitzharding at the Hospital for Sick Children in Toronto, trying to identify high-risk babies discharged from our nurseries who have a 10 percent or greater chance of some neurodevelopmental handicap, the idea being to give to these babies specialized and intensive rehabilitative care after discharge. She included in the high-risk groups those with birthweight less than 1,500 grams; those with gestational age less than 33 weeks; those with double jeopardy, that is both premature and undergrown for gestational age; those with meningitis seizures; ventricular hemorrhage; and severe chronic lung disease.

Now if you notice, the figure in brackets is the percent overall that she felt to have neurodevelopmental handicap on follow-up from these high-risk groups. Now as one looks at the figures, we classify ourselves into optimists and pessimists. We can say, well, these are the worst of it, and yet none of these figures is more than half, meaning that the majority in each group turned out to be basically doing well on follow-up. Or, one can say, but these are substantial numbers of damaged babies being produced by our well-intentioned intensive care, and we will have to cope with them. We will have to learn how to give that care and we will have to learn to give the aftercare the children need.

Now, according to your view of the world, you can look at these figures in one way or another. The cost that this kind of care, for all its good results, lays on the taxpayer is not inconsiderable. About 6 percent of all newborns require nursery intensive care. The length of stay on the average is about 13 days. The number of units around the country is about 450; average cost per patient, about $8,000. Patients needing a nursery intensive care unit, in a year, number about 200,000; patient days within the United States, 2.5 million; annual cost, $1.5 billion. Now, again, it depends on your world view. How many B-1 bombers is that? Not so many. For myself, I am partial to babies and to their welfare, and I do not really think we need B-1 bombers, so I agree with the preventive motif here. You can go mopping up this spillage in a very expensive way, almost forever, but turning off the tap is clearly a more efficient strategy.

Now, because I have been in the field long enough, I am a swami and can give my predictions about the future and so I will indulge myself by doing that. Well, Dr. Avery, where will this all end? Are we going to be taking care of smaller and smaller prematures until we have artificial placentas, reaching back into the first and second trimester, or is there a floor, an end to it? My answer, at least for now, is that there is an end to it. This is a depiction of the development of the lung, budding from the primitive digestive tract with dichotomous branching; here it is beginning to look sort of lung-like. But at five months gestation, the blood vessels are still not in close vicinity of the air passages, so effective gas exchange is not really possible. The time that it takes gas, especially oxygen, to defuse between the air passages and the capillaries is too long for the needs of a rapidly growing, metabolically active fetus. So if a baby is born before about 24 weeks, it essentially is missing one vital organ, its lungs.

I, therefore, predict that our scorecard will improve steadily in the prematures born at 24 weeks; before that age we will have very little success, short of using a membrane oxygenator or an artificial heart-lung

machine, keeping a very immature baby alive until its lungs grow. And I think that is out of proportion. But I think we can, with the babies who are old enough to survive, do better and better.

We had an argument in our nursery at one point. We had a period during which our number of available beds was very tight, and we were having to turn away babies because there was no room. We were arguing that the outcome for a baby weighing less than 750 grams was so bad in terms of odds, that maybe we should refuse that baby in order to have the bed available for a baby who had a better chance. You know, it is kind of Draconian, but with only so many beds and so many respirators and so much staff, it was the kind of choice we faced.

But two things happened during that time in our unit. One was the birth of a premature baby of about 700 grams; the resident explained to the mother how many things could go wrong and how uncertain was this baby's outcome. The mother listened with a kind of strangely tranquil look on her face, waited until the resident had wound himself down, and then said, "Yes, I know, Doctor, but my other child weighed 50 grams less and you all cared for that child in this hospital three years ago and she is fine."

Now, supposing that woman had been the one on the other end of the phone when we decided, no, we cannot be bothered any more with babies less than 750 grams. It is very difficult when you are dealing with an individual and not a statistic to make that kind of decision.

Another problem is that individual babies come through, I almost want to say, in spite of us. They seem to want to live and they belong to somebody and have a name. This baby's name was Mary and she weighed 670 grams at birth (about 1.5 pounds), and she was on a respirator in our nursery for six weeks. She was in the nursery itself for 3.5 months and here she is at 18 months. She came into my office [next slide] when she was 5 years old and drew this picture of herself and wrote her name at the bottom.

Here she is at one of our reunions. She is now doing very nicely in the third grade. Now, whenever someone says, "We can't do any more with those little babies," I always ask myself, how do we know which one is Mary?

Keynote Panel

Social Issues

by Jane Mercer, Ph.D.
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I have been asked to talk about the sociocultural aspects and issues of mental retardation. There are three empirical findings that are generally accepted and I want to present those first and then go directly to the policy issues.

First, there is clearly an overrepresentation of persons from low socioeconomic status and from sociocultural minorities among those who are labeled as mentally retarded. These differences have been recognized for many years. Second, empirical research shows very clearly that there are two distinct groups that have been labeled mentally retarded. You will notice this is a diagram that comes from an early study by Dingman and Tarjan. There is one group with identified organic anomalies and another which shows no evidence of organic anomalies. The organic group tends to have IQs that fall below 50. They form a separate cluster below the normal distribution curve for scores on intelligence tests and have an average IQ of approximately 35. The nonorganic group falls primarily in the mildly retarded range with an average IQ in the 60s. Their test performance falls within the normal distribution of IQ test scores.

The Action Agenda, as it is now drawn up, focuses almost exclusively on that small group, whose IQs fall generally below 50. This group comprises between 15 and 25 percent of those who are identified as mentally retarded or developmentally disabled. I would like to focus on the other 75 percent, the group referred to by Dr. Gallagher, because I think it is important that the Action Agenda include some type of program aimed at prevention of mental retardation in this group. If you look at the charts, which deal with the prevalence of organic anomalies, we are talking about one person, two persons, six persons--very small numbers. Those numbers are important. But we must not forget, in our concern for the organically damaged, the larger group that has no organic anomalies, but is still functioning at a mentally retarded level.

A third research finding is that the organic group generally does not show an overrepresentation of persons from low socioeconomic

backgrounds and sociocultural minorities. It is the nonorganic group that generally shows an overrepresentation of minorities and sociocultural minorities.

Three Models of Mild MR

There are five theoretical models which I have presented on other occasions to try to explain the above findings. I will discuss only three of them briefly, and I will concentrate primarily on the third.

The first model is the one the Action Agenda as it has now been presented, focuses on almost exclusively. The model argues as follows: Sociocultural factors produce socioeconomic status because persons from lower socioeconomic levels and sociocultural minorities show an increased rate of exposure to biological hazards of various kinds, which in turn produce a higher rate of biological damage, which results in a higher rate of mild mental retardation. The Action Agenda is very concerned with the problems of adolescent pregnancies, low birthweights, prematurity, poor prenatal care, poor perinatal care, alcohol, drugs, smoking, early identification and intervention, malnutrition, child abuse, accidents, and so forth. To the extent that those hazards occur more frequently among persons from lower socioeconomic levels and sociocultural minorities, they are factors that may be significant in producing higher rates of developmental disability in these groups.

I would like to turn now to a second model, essentially the model implied in Dr. Gallagher's presentation. This explanatory model hypothesizes that group membership again leads to differing sociocultural and socioeconomic states which have different parenting skills and adult role models. In minority groups and lower socioeconomic levels, there is less stimulation and interaction with the child, which leads to limited cognitive stimulation and fewer mediated learning and language learning experiences, and produces a higher rate of mild mental retardation. Many investigators--Rames, Heber, Feuerstein--have focused on this cognitive stimulation model. It is certainly important in setting a policy agenda. What are we going to do, in terms of prevention of mild mental retardation, to increase cognitive stimulation for children from high-risk backgrounds?

The third model is one I have spent time investigating. This model focuses on the role of social institutions, such as schools, in producing mild mental retardation. It argues that group membership leads to socioeconomic disadvantage and sociocultural distance from care institutions. The tests and diagnostic procedures as well as the school curriculum are culturally loaded with core cultural materials. As a consequence, there is a higher rate of misdiagnosis and miseducation of persons who come from sociocultural minorities which produce the observed higher rates of mild mental retardation in these groups. This particular

model is not a popular model because it says that many of our institutional procedures are, in fact, producing the mildly mentally retarded through processes of miseducation and misdiagnosis.

Social Policies for Prevention of MR

A panel of the National Academy of Science recently published a report called *Placing Children in Special Education: A Strategy for Equity*. Dr. Gallagher and I were on that panel. I would like to convey the message of that report to this conference as you begin to think seriously about social policies for prevention of mental retardation in Virginia.

The questions posed to the panel by the Office of Civil Rights, which funded this effort, was, "What is wrong with the diagnostic procedures which are producing an overrepresentation of minorities in special education? How should we change the testing and diagnostic procedures so that they will be more culturally fair?" After a year of discussion, the panel concluded that we were addressing the wrong question. The problem was only partially with testing or assessment procedures. A much more fundamental problem was the educational institution as it now functions. Could the schools contain obstacles to the growth of some children and perhaps create mildly mentally retarded persons because of faulty institutional processes? In the middle of its term, the panel changed the question it was addressing and reached the following conclusions. It concluded that children were categorized and assessed much too soon in the referral process. We need to reorganize educational institutions so that the assessment process would come near the end of the intervention process and would probably affect only one-fourth of the children who are now typically run through the standard battery of tests. Instead, a system of interventions is needed which can be applied, without labeling, as soon as the classroom teacher has identified that a child is at risk of failing because he is not learning. We recommended that multiple educational interventions using remedial specialists, psychologists, special educators, and other consultants should be immediately available within the regular classroom when the child begins to have learning problems. Rather than using global IQ tests and general measures which do not provide any information of particular value in designing educational programs, all testing should be functionally related to the educational program itself. Only tests functionally related to academic problems such as reading, math, cognitive processing skills, adaptive behaviors, and physical problems are justified as diagnostic tests because they lead to treatment.

The panel proposed that differential labels should not be used, except for the purpose of identifying children who need specific educational interventions. The global categories we now use, such as mentally retarded and learning disabled, are not diagnostically very

useful. They do not lead to specific treatments, and they can get in the way of an adequate educational program. We felt the special education staff should be required to demonstrate that their programs are of high quality and effective and that the children placed in their programs will be better off than if they had remained in the mainstream classroom.

Multiple Educational Strategies

In this report, we proposed that multiple educational strategies should be used in the regular classroom before the child is moved into special ed. Our panel estimated that 60 to 70 percent of the children who are now labeled as mildly mentally retarded, especially those from lower socioeconomic levels and ethnic minorities, would never be referred, labeled, and placed if appropriate educational strategies were available in the regular classroom. The next question, of course, is, are there appropriate strategies now available? What sorts of interventions should be used?

The Office of Civil Rights pursued this question by funding another project that was a follow-up to the National Academy proposals. This project was to identify effective and exemplary programs throughout the country that were being used in the regular classroom to prevent mild mental retardation, often called "functional" mental retardation. They found about five such programs. All shared certain generic characteristics. First, all of these exemplary programs were geared to increase the amount of "time on task." Observational studies in typical regular classrooms have shown that a student might actually be engaged academically for *less than 10 minutes a day*. The numbers are astounding. In some classrooms, it was less than two minutes a day. So, the first issue in preventing funcational mental retardation is to reorganize teacher behaviors so that the children are engaged academically--not just passing out papers, lining up for this and that, or listening to somebody else read. Not surprisingly, whenever academic time is increased, there is a direct positive correlation with increased academic achievement. It seems rather a simple-minded notion, but this has been one of the discoveries of educational research in the last five years.

There are numerous well-documented programs for teaching teachers how to organize their classrooms to increase time on task from 10 minutes a day to two hours or more a day. I can recommend books for those of you who are interested in how to do this.

The most effective programs involve a great deal of teacher-directed instruction--quite the opposite of what has been happening in classrooms for 20 years. Very teacher-centered, structured programs are most effective. A great deal of positive reinforcement is used. Interestingly enough, a rapid pace of instruction is most productive. The slower the child's learning rate, the faster the instruction pace should be. This

principle seems the opposite of what one would expect. Because a slow-learning child's attention time span is short, when instructional materials come rapidly, he is cognitively engaged and keeps on working. Thus, rapid-fire instruction is more effective than the slow approach.

Research has also found that there is not enough practice in the typical classroom. Teachers present material one, two, or three times and expect the child to know it. Some children need to have the same material repeated 30, 40, 50 times. Many middle-class children get practice at home, but children from lower socioeconomic levels frequently do not. Reorganizing the classroom to allow for a great deal of repetition, rerunning material through the synapses, but doing it in a dynamic and interesting way keeps the students stimulated. Interestingly enough, one of the most effective procedures is to use choral responses in the classroom. We are rediscovering what teachers knew and practiced 50 years ago.

Merging Effective Programs

Effective programs carefully monitor individual progress by constant testing, feedback, retesting, so that the teacher knows precisely where each child is in the curriculum. I am going to briefly discuss five of the effective programs identified in the Office of Civil Rights study. The programs have much in common, but each emphasizes a slightly different aspect of how to structure educational environments for academic achievement. What we need to do is take the unique aspects of these programs and make one really superior direct instructional program to prevent functional mental retardation in very high-risk populations.

One of the most promising programs, I am sure some of you have heard of it, is the *Distar* program developed at the University of Oregon. In a national study conducted at many different sites, the Distar program out-performed 12 other programs. Not only did the children have better basic skills, but they also had better self-concepts. Some other programs focus directly on self-concept, Distar does not. It focuses on teaching basic skills using a highly structured curriculum and teaching procedures. Nevertheless, it also produces the most positive self-concepts in children.

Exemplary Centers of Reading Instruction (ECRI) was created with funds from the U.S. Office of Education. It has a very clear program for teaching teachers how to present materials in class. It does not involve a specific curriculum. Its authors argue that it does not matter what the curriculum is, if the teacher knows how to present it, she can be successful. Their presentation methods use fast-paced choral responses. Even adults in a workshop I attended were excited as they taught us to read phonetically using their procedures.

Precision Teaching, from Montanta and Utah, has also been very effective. It emphasizes testing and having the child keep track of his own progress with progress charts that are highly motivating.

At Juniper Gardens in Kansas City, researchers from the University of Kansas have developed a very effective program using *peer tutoring*. They increase time on tasks by pairing students in a carefully controlled situation. One student acts as tutor and the other as teacher. Then they reverse roles. Both of them are involved in this interchange. Peer tutoring itself, with nothing else, shows good results. What if peer tutoring were used in combination with these other approaches?

And then finally, Slavin at Johns Hopkins University, has been doing research on *cooperative learning*. He has shown that cooperative learning using teams is very effective in desegregated schools. Putting the slower learners on teams with faster learners and using a rather elaborate process of scoring to increase motivation increases achievement. I do not know of anyone who has used cooperative learning with children who are handicapped or disabled or in mainstream programs. I do not see any reason why it should not be an effective intervention in this context, just as it has been in other contexts.

I hope that in developing your Action Agenda you will address the need for prevention of functional mental retradation. I realize it is more spectacular to develop marvelous medical interventions for those with organic anomalies. But we have technologies now which can make a real impact on preventing mild mental retardation. I am not sure whether you call that primary prevention or secondary prevention. But I am sure that with appropriate educational interventions, a large percent of the youngsters who now end up functionally mentally retarded would *not* be functionally mentally retarded. Please take them into account as you prepare your agenda.

Keynote Panel

Feasible Goals for Prevention of Mental Retardation and Other Developmental Disabilities

by Hugo W. Moser, M.D.
John F. Kennedy Institute for Handicapped Children
Baltimore, Maryland

Four weeks ago, I participated in a meeting at the Kennedy Library in Boston, an oral history dedicated to mental retardation prevention. It brought home the following point. In the late 1940s and 1950s, there was a very significant movement to improve the care of the mentally retarded. People who are only a few years my senior, such as George Tarjan, Sam Kirk, Elizabeth Boggs, Gunnar Dybwad, Grover Powers, were the leaders who pioneered this new approach in thinking toward mentally retarded. This meeting at the Kennedy Library brought home to me the tremendous support and national prominence which was given the field of mental retardation and developmental disabilities during the Kennedy era and, to some extent, since then. Hallmark legislation, such as Public Law 88-164, the Mental Retardation/ Mental Health Facilities Construction Act, was so important in the lives of many of us. I, myself, am strictly a child of Public Law 88-164. All my professional life has been associated with that law. If that law had not been passed, I believe that I would be looking after stroke patients in Boston. My life was totally shaped by it. I suspect that for some of my colleagues, such as Allen Crocker, Harrie Chamberlin, and others, their lives may also have been influenced by that law. Multiply it many times over, and, to the extent that we have been helpful, that legislation certainly had an impact.

The question then is, are we committed enough, smart enough, motivated enough, and successful enough, so that this effort can be now maintained, without it representing the degree of national priority that it did in the 1960s? It is a very important question. I feel positive about it, influenced to a considerable extent by the attendance here of more than 400 people. I believe that the answer to the question is a strongly positive one, but I want to make some remarks that will support this and also point out some concerns and feelings about how to best go about it.

Priorities in the Action Plan

Priorities in the action plan that has been presented here, and two documents entitled "The Golden Twenty" and "The Thoughtful Thirteen," by Allen Crocker, give a beautiful prescription on how to go about prevention.

There are certain things that are a common thread. First, focus on serious problems that we know how to solve, such as the prevention of measles, infectious diseases, the hallmark work on PKU, hypothyroidism, lead poisoning, and Tay-Sachs disease. The specific programs that have been highlighted are strongly carried out in this state--they have great intrinsic value. By being cost effective and highly demonstrative, they have a strong amplifier effect. They reinforce our confidence that prevention can work and will allow us to go on to other objectives in the field.

A second general principle is to go after the "biggies," if you will, to go after the problems that represent major issues. We have seen the strong emphasis on mild mental retardation. The tremendous efforts in dealing with the small newborn and improving neonatal care and the very major efforts in respect to Down's syndrome are, of course, all examples of programs that address the major numerical and important issues in the field of retardation.

And, third, the very strong emphasis on planning. As Dr. Dybwad commented at the Kennedy Symposium, before Public Law 88-164, the first federal initiative was to encourage or demand of the states that they each develop a state plan. Such an overall planning effort is beautifully exemplified by this meeting. Now, we have every reason to be hopeful, yet there are a number of things of which we need to be aware. I have lived in Baltimore for seven and one-half years now and have had the chance to observe very closely and with great interest two trends that are going on simultaneously. One is the Inner Harbor, which is magnificent. More people are coming in, it is jelling together. The aquarium is bringing more people to the convention center, hotels are being built, it goes on and on. Yet, three blocks north of it is Howard Street, which used to be the major shopping center, but is now a wasteland. One sees, then, two trends going on. A tremendous improvement in some areas; yet, a continued downward trend in other areas. What is going to be the end result?

I have a concern about our field in this same way. We have success stories in the detection/prevention of metabolic disease, some success in dealing with toxic agents, great success in neonatal medicine and infectious disease, yet at the same time there is a great increase in the incidence of adolescent pregnancy. There is a deterioration in the environment in terms of school support for many other adolescents. So,

where the equation will end up is a real question. I have a strong sense of optimism about our cause, but we have to be strongly aware of the goals we have to achieve.

Conflicts in Prevention

One of the hazards I would like to point to is that prevention, by its very nature, cannot compete and appeal through publicity, if you will, to treatment and cure. It is hard for a person to continue to be excited about the fact that he or she did not develop measles encephalitis. We know it is great that it is prevented, but it is not what we spend our time thinking about.

The second problem that came home to me at a meeting at the Kennedy Institute about a year ago, is that as we talk about prevention we have to be aware that it carries a risk of devaluing people. There is now a mouse model of Down's syndrome and it is possible to study some of these issues in the experimental animals. We had an experimental embryologist, a very capable person, presenting this material to our board of trustees. But speaking as an embryologist and not as a clinician, he spoke about Down's syndrome as something to be avoided or prevented at all costs. One of our board members has a granddaughter with Down's syndrome. I was listening to this presentation describing all the efforts to eliminate Down's syndrome, realizing how it would affect a person who has a grandchild with Down's syndrome. Who wants to be something that is to be prevented? Prevention is great, but it has to be balanced and care has to be taken to not overdo one's enthusiasm.

In practical terms, I advise with great emphasis that money for prevention must be very carefully pre-assigned and categorized for that purpose and not be put into direct competition with money for service funds.

There are a number of other conflicts. Dr. Tarjan spoke so eloquently about the fact that the nature versus nurture conflict is dead. It should have died many years ago, but there are many problems of balance and priority-setting, and they have to be faced as real conflicts.

Biomedical vs. Behavioral Issues

Another conflict is the issue of support or focus on biomedical prevention versus prevention using behavioral or social techniques. I think Dr. Gallagher pointed this out so clearly this afternoon. He was talking about the "magic pill" for prevention of biomedical issues and the great appeal that concept has. It has such an appeal, in part, because when it works it can be so effective and dramatic. Furthermore, it does not demand major changes of us. Whereas, as Dr. Gallagher was pointing

out, the approach to dealing with behavioral issues, sociocultural disadvantage, and mild retardation, requires a much more personal input from us as individuals and as a society.

In 1967, I attended the International Conference on Retardation in Montpelier. At that time, I was a perfectly innocent neurologist who knew nothing about mental retardation. It was at that time that I heard Dr. Herber's presentation about the Milwaukee project, became vitally interested in that topic, and have followed it very closely since. I have written a number of grant applications to try to follow through on these principles and to introduce them to the Baltimore area. I have been totally unsuccessful in receiving any funding for such applications, whereas I have continued to be successful getting funds for the much more circumscribed biomedical projects. Probably it is a sign of wisdom of the grant givers' judgment that people should stick to the latter, but I only indicate it for the sense of importance that I, both as a human being and as a researcher in the field, attach to the balance between biomedical research and behavioral research.

I am concerned that within 100 feet of the Kennedy Institute more retardation may be created each day than we are curing there. I believe it is a major failing of our system that we have not at this moment been able to carry out on a large scale the programs that Dr. Mercer and Dr. Gallagher talked about so convincingly.

I feel that it is of very great importance, as the afternoon papers indicated, to study precisely what factors help and hinder. Again, Dr. Mercer's demonstration that interactive academic time in school was less than 10 minutes a day is such a vivid example of our shortcomings. I also had an experience with the power of carefully and skillfully conducted behavioral research through my friend and associate, Dr. Mike Cataldo. Dr. Cataldo has worked with Dr. John Freeman, who is in charge of the Epilepsy Clinic at Johns Hopkins, with the problem of many adolescents with seizure disorders failing to take their medications. Dr. Cataldo, being an extremely able behavioral psychologist, examined what we can do to relieve that. He tried a number of things and then came up with a method which has worked perfectly. Namely, the teenagers get a lottery ticket if their blood level of dilantin or phenobarbital is satisfactory. And, in fact, it worked so well that most of them developed blood levels twice the therapeutic level. I am also obviously aware of the work of Dr. Christoferson in Kansas in regard to finding effective behavioral techniques to encourage use of seat belts. So as we talk about the behavioral field, the message that I want to give is that prevention is both behavioral and biomedical and that the two are to some extent in competition. It is unavoidable and, again, I would think society has to categorize funds for each and not have them be directly in competition with each other.

I fear, as is true of my own research experience, for reasons I do not fully understand, that biomedical research gets funded more easily than behavioral research. Having all my publications in the biomedical area, I am allowed to say that.

Support New Research

I just have a few more things I would like to say. Another source of conflict is the division of labor between applying what we know how to do and searching for new answers. Clearly, as was pointed out this afternoon by Dr. Oakley, Rh prevention now is applied in 90 percent, but not 100 percent, of the cases. It is inexcusable not to have it at 100 percent level and you can point to such failings in many other programs. I think your state and others are doing a very fine job in seeing that we do apply without fail what we know how to do. But then, for heaven's sake, do not throw out the support of new research.

There are many reasons for my saying this, but let me just cite a couple. Research can be like the "that's good, that's bad" kind of story. We all know severe retardation due to phenylketonuria can be totally avoided as the result of the programs started by Dr. Guthrie.

On the other hand, we realize the problem created by PKU women who now will bear children and would not have in the past. Unless we see that they receive proper care during pregnancy, there will be as many children retarded due to PKU as there were before our screening program started. So here a new and different problem has been created as a result of new knowledge and we cannot stand still. We have a new problem that we did not have before and new continued research is absolutely necessary.

We have eliminated, to a very large extent, measles encephalitis, but herpes encephalitis incidence is increasing six-fold. Again, it is a new problem that we have to learn how to deal with. As I think you all know, we are just on the threshhold of fantastic advances in the field of genetics. Within the last few months, a marker for Huntington's disease has been discovered. It will be possible to identify carriers of Huntington's disease. The prospects of genetic counseling are truly astounding.

The same appears on the horizon for muscular dystrophy, and may, in the very foreseeable future, apply to the majority of genetically determined disorders. So the opportunities for counseling and prevention are something that we can only begin to conceive of now. There are opportunities for therapy that are just on the threshhold. I am going to just cite one therapeutic experience that I heard about. There is a form of Gaucher disease in Sweden in which normal adolescents, as they reach young adulthood, develop a progressive dementing disease leading to very serious disability. Dr. Lars Svennerholm, in Goteborg, presented a paper

recently on a successful bone marrow transplant in a patient with Gaucher disease and the very strong likelihood that the transplant will be successful in dealing with the problem.

Now, when the child was 11 years old and the issue of a bone marrow transplant first came up, there was no matched donor available. The family had another baby, conceived for that reason. It served successfully as a donor to treat the sibling afflicted with Gaucher disease. Now, obviously, we will have to do better than that. I suspect that transplant therapy will improve a great deal. There are questions of genetic engineering which will, in some years, introduce therapeutic possibilities.

I caught myself just then, as I told this story, falling into my own trap. Namely, I have again given an example of the glamour of therapy versus prevention. The costs of that one bone marrow transplant I think could support the Virginia Genetic Screening Program for a full year.

Yet, as Dr. Avery pointed out this afternoon with the 650-gram baby, if you are faced with the possibility of providing treatment for someone who is severely disabled, there is just no way it cannot be done, that it can be withheld. It again highlights the tremendous importance of recognizing that prevention needs to be supported with its own budget and be protected from the tremendous appeal and expense of curative therapy.

Need for Accurate Figures

I would like to finally highlight the point that Dr. Oakley made--the need for a scorecard. Dr. Oakley said that the data we use for the most part on the incidence of retardation are 10 or 15 years old.

One point he made was important and new to me. Thirty-seven thousand people with genetic risk were identified personally, and he found that, in the way in which it was done, this personal identification did not appear to violate privacy issues. This is a controversial issue, and the need for identification must be balanced with the right to privacy.

The need for accurate figures is great. First, accurate figures enable us to determine if a new danger is rising in society. How would we know whether dioxin or a certain chemical causes something unless we have figures on unusual incidence? Secondly, accurate figures are needed for us to maintain credibility. Having been long, long ago now, a foreigner to the United States, I continue to be impressed and overjoyed by the advocacy toward the handicapped that exists here, the feeling that we all have a chance, that we can all improve ourselves. The rejection of Malthusian principles I think, perhaps, is the most precious possession we have.

Now, there is a potential conflict between marketing and credibility. Can we in fact achieve a 50 percent rate in the incidence of mental retardation by the year 2000? I am sure there is a proper line that can be drawn between realistic expectations and making our goals vivid and exciting to the general public. At the same time, and this is where the scorecard is totally indispensible, I think as funds are directed toward prevention, toward management of handicapped people, we must stand accountable for what we do in terms of incidence of retardation and, equally important, in showing that our services are, in fact, effective for the clients we serve.

I would like more than anything else to emphasize the point that if we lose our credibility with the general public, we lose everything. So the very thorough examination of the facts this afternoon and tomorrow is what I find so pleasing about this conference. I want to close by saying that I find myself totally overwhelmed by what this organizing committee has done in terms of bringing together 400 people from the state agencies, voluntary agencies, consumer groups, the President's Committee, and people from all over the country. And I know what it means to bring together and pull off a conference like this. I think it is an exciting and marvelous undertaking, and I am proud to have participated and want to congratulate you on your effort.

Keynote Panel

Prevention of Developmental Disabilities: Fundamental Considerations for Public Policy

by Allen C. Crocker, M.D.
Children's Hospital Medical Center
Boston, Massachusetts

In my view, this has been an altogether astonishing conference in which the investment and the involvement of the planning group have been enormously apparent. It is one of the finest conferences on prevention that has ever been held, and I wish to salute all of those whose work has made it so exceptional.

I had the opportunity in November of 1979 to join you at the previous prevention conference, the one that was held in Richmond, and I was asked at that time to talk on the topic of prevention: what are the priorities? I was newer in the game then and went over a large collection of elements in prevention which seemed to me germane, and I had a very uncomfortable moment of truth as I was getting toward the end of my talk because I was supposed to come to the conclusion as to what should be the priorities. I punted broadly and said, in prevention of mental retardation,every preventive measure is appropriate. What are the priorities? All of them. I was troubled with myself for being so benign at that particular moment and, in the years that have followed, I thought that I could determine which of them were surely more important than others and deserved to be on the list. I am notably heartened on coming back to Virginia to find that as this group has constructed its Action Agenda, they have seen fit to include all of them in it.

Just so that you can keep score, the issue of public policy is a territory so broad that one could go on forever. I decided to limit myself to these four points.

First, I would like to abstract some comments from conference sessions that have occurred in the last two days which relate to policy. Second, I would like to share with you a diagram which shows my notion of how policy comes to be established. Third, I would like to list what I consider some very special features about the prevention field which impact on policy formation, and, lastly, I would like to have a little exercise in considering whether there can be projections from the experiences in Virginia to elements of a national policy.

Policy Issues Omnipresent

I, I resolved that in taking notes during the conference sessions, I would limit myself specifically to policy matters. This proved to be a more compelling assignment than I could have imagined, and I came to realize that issues leading into policy are omnipresent in discussion of human services affairs.

Let me just mention a few. I would like to draw particularly on Wednesday afternoon. Howard Sparks commented that the conference in 1979 had, in point of fact, led to three specific outcomes, three action results, he called them: the activation of the birth registry, changes in education programs, and the foundation of an Office of Prevention in Mental Health/Mental Retardation. This intrigued me in the sense that the path to policy was clearly under way in the previous conference.

Dr. Fisher made two statements about policy that caught me especially. The first he said was, and I quote literally, "Virginia is remiss if it does not do more in prevention." The second was an intriguing one in which he said, "Prevention is a nonpartisan issue."

George Tarjan naturally made many comments that relate to policy. One of them troubled me at first, but I think we can all work with it. He said, "In this country health is not a right," and he was contrasting it with free speech or bearing arms. He further commented that policies in the health area tend to be set by healthy people, which was a caveat that we should remember. He indicated, as did one or two other speakers, that perhaps we should indeed have a national plan for prevention activities, and he was further so audacious as to turn to the conference attendees and say, "You carry the hope of mankind."

Godfrey Oakley made a number of comments that lead to policy. The one that I will remember particularly was his insistence to get a scorecard. Remember that one. He also pointed out in a dramatic slide, that neural tube defects have their highest incidence in the Southeast of this country, something that should be remembered by planners in these states.

Gordon Avery was offering us many thoughts about babies. He used a phrase that I thought was particularly cogent when he said that there is double jeopardy for premies who are sent home to troubled households. At that point, he set a theme which would recur again and again about attitude and multi-factoral elements. He also was courageous enough to conjecture that perhaps 24 weeks of gestation is the ultimate cutoff for survival and for the efforts of the perinatal therapists.

Jim Gallagher, again and again, brought out the notion that many mysteries remain regarding the dynamics of early childhood, and in a parallel fashion, with the phenomenon referred to as mild mental retardation, he gave much information that would suggest that we are dealing with multi-factoral elements in that circumstance.

Dr. Mercer made many important comments. The one that recurred in her presentation was that services are often appropriate before labeling, and she suggested there should be assessment for educational functioning, rather than the utilization of global IQs. She seriously questioned whether the term "mild mental retardation" was appropriately as a basis for educational affairs or whether there should be substantial reform in our educational intents.

And finally, Dr. Moser pleaded that the money for prevention be protected and that it should not be in competition with service funds.

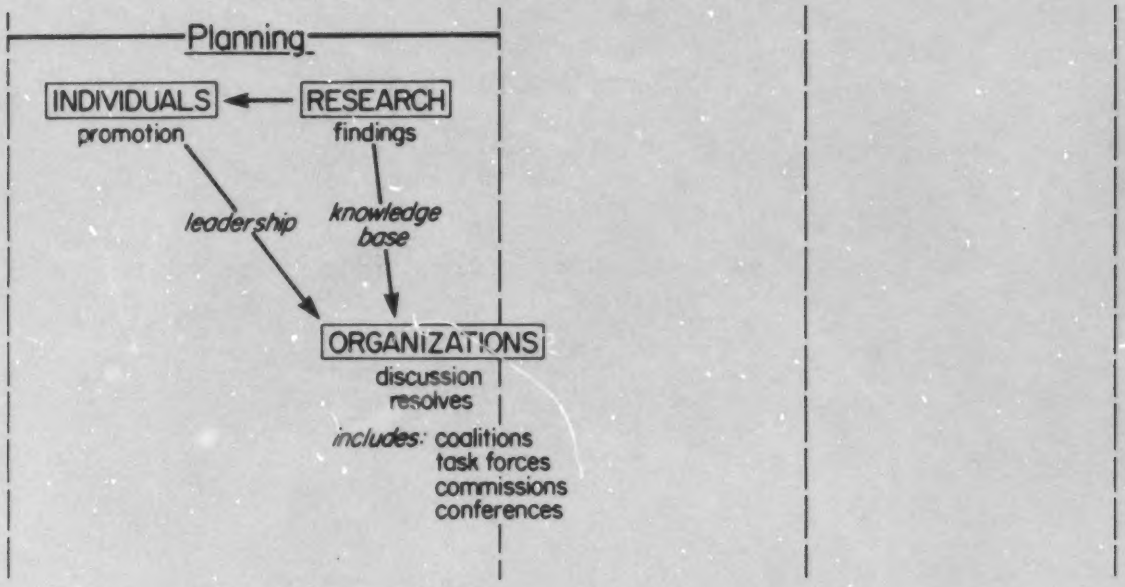
The speakers who have joined you in this conference are saying that, if we act in faith, these guidelines will lead us to control many of our actions; they are the cornerstones of public policy.

Policy Formation

II. I was asking myself as I was listening to these presentations, just how does policy come about? What eventually determines the characteristics of what we do and what we believe in? It seemed to me that there were three phases: the first phase is appropriately called "planning" and this should be very familiar to you all (Figure 1). There are contributions which come from individuals who promote the things that they believe in and provide substantial leadership. They help get us together. By the same token, there are research findings--elements which will eventually add to the knowledge base--which not only inspire some of the individuals, but feed directly into a sense of obligation for those who gather, who have discussions, and who form resolves. One form of resolve is the Action Agenda.

POLICY

Figure 1



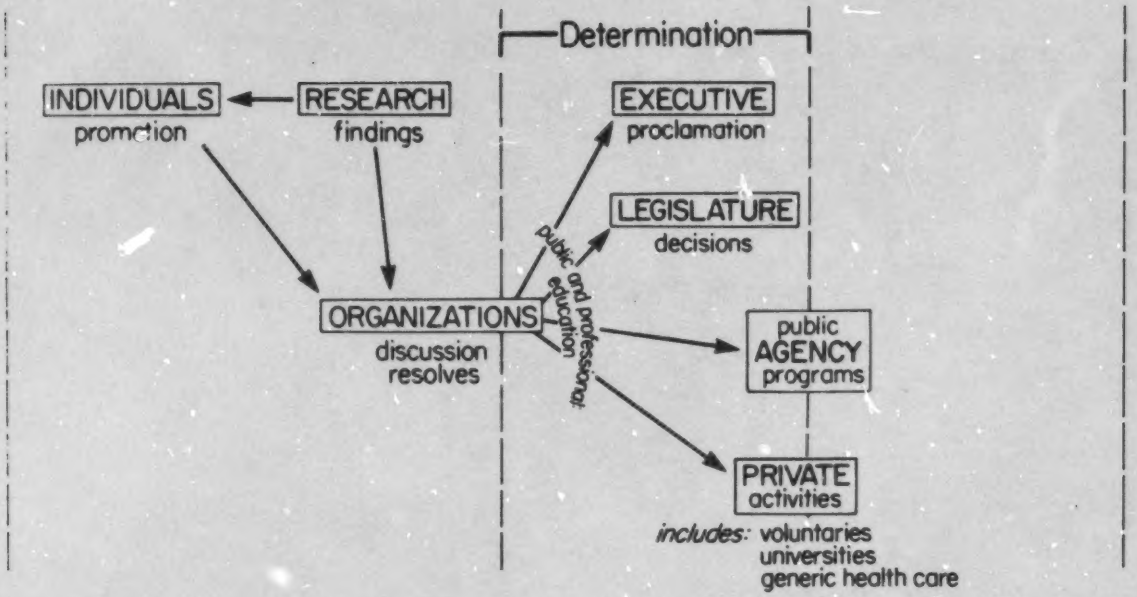
Elements of Policy Formation

The gatherings can come in many different forms. They are often based on coalitions and we will mention this again in a moment. Sometimes, they have a concrete assignment and are labeled as task forces. Sometimes they have more durability and are called commissions, but, on a friendly basis, let us just say they also can be conferences.

This element, the planning element of policy formation, is the root. The next step is when we go from simple planning into a stage which is called "determination" (Figure 2). The organizations and their resolves have an opportunity to affect many components in our society. They can, for example, affect the executive branch. I call your attention to a remark which Governnor Robb made yesterday when he said that the outcome of this conference will guide our actions.

POLICY

Figure 2



We can also reach out to the legislature, most critically, to public agencies, and also to the very substantial body of private programs and agencies.

I have labeled this process of reaching out in the period when policy is being determined as "public and professional education." There are all kinds of synonyms you could use just as well, but that catches the notion of informing as well as urging.

The private agencies that I am referring to would make an endless list. I call attention particularly to voluntaries that have many elements of potential action, the universities and, just to keep them alert, the generic health care system members.

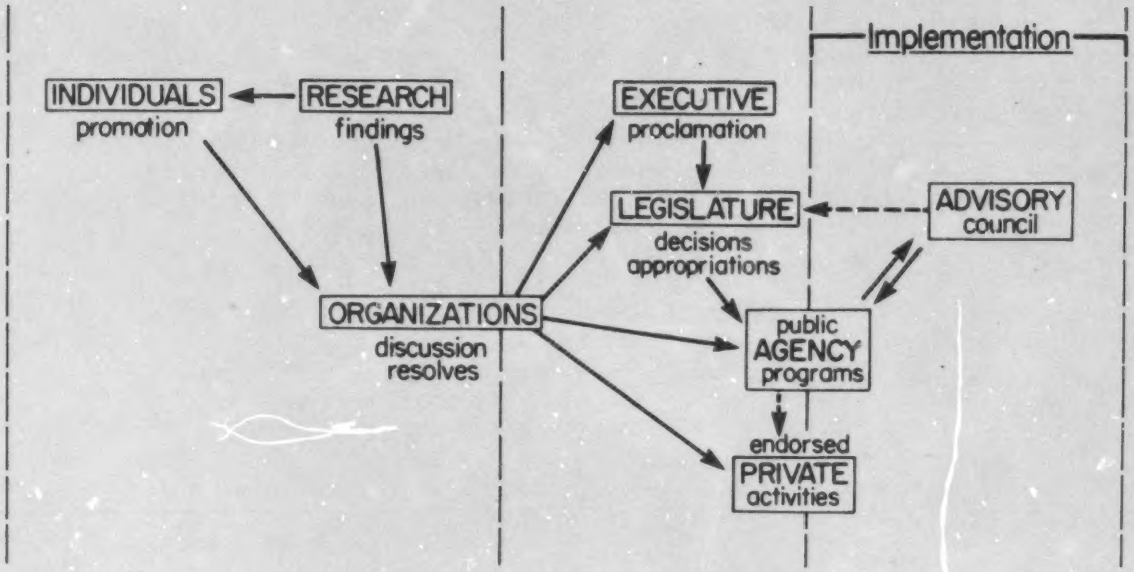
In this period when policy is being determined, there is a lot of action, a lot of give and take, a lot of challenge. Eventually, however, it has to get to the third phase which is "implementation" (Figure 3).

Here the arrows start to become wilder and, in point of fact, it is impossible in a two-dimension diagram to put in all the arrows. I have put in a few key ones. If good fortune is with us, promotional elements

can come from executive components. The legislature, one hopes, makes some decisions as to appropriations; one hopes that with this, a great cascade of fresh commissions arise in the area of the public agencies.

POLICY

Figure 3



The public agencies, on the other hand, quite appropriately can endorse private activities. That term "endorse" can have a whole series of implications. It can lead the way to the ability to receive reimbursement for services. It can be a shared piece of the mission in such elements as public education or many other innovative programs that the flexibility of the private agencies may allow.

Somewhere as this process of implementation is getting under way, there has to be some sort of a watchdog element, which, for want of a better name, I have referred to here as an advisory council. Where that resides is an individual and local matter. As I have a chance to talk with other people in the prevention field, I find that those elements can reside many places. They can reside within an agency and that agency can be MR-oriented as it is in this state. They can reside in the Health Department, in conjunction with Developmental Disabilities Council, or in sort of a free-flow fashion like the Children's Services Commission in Tennessee, which reports, by and large, directly to the governor. But there needs to be somewhere a chance for the process to be monitored and enriched.

III. As we look at the field of prevention, what are some of the elements that are particular to policy formation? It seems to me there are about six of them:

The *first* one is kind of a mystical one. Without our really thinking much about it, prevention has become a movement. It is interesting to speculate, and I would urge you to do so in your own satisfaction, why this has come to be. There is the theme in the prevention field of a vast promotion of the human condition. This appears to be a unifying force. There is implicit the notion that there will be an enhancement of the full potential for young people and, in fact, for all people. This seems to lead to a will to collaborate. The fact that your conference planning committee hoped for 300 and got over 400 people here suggests that, indeed, prevention is a unifying and an activating concept.

The *second* element that is particularly prominent regarding prevention policy is the fact that there is, inevitably, a multiplicity of agency and facility involvements. For example, there can be no discussion of any meaning in the area of prevention of developmental disabilities that does not include as participants, representatives in health, mental health, mental retardation, education, social services, and developmental disabilities. That is a lot of people to get in the room.

But they all come, and the intriguing element of it is that the sum is clearly greater than the parts. I would suspect that the interagency phenomenon has been more effectively fused within the prevention movement than in any other. Certainly, in conventional therapeutic services it is nowhere near as impressive.

The *third* element that shapes the discussion and establishment of prevention policy is that there is within the assignment a bewildering divergence of programmatic focus. For example, we are sometimes working with an established procedure such as Tay-Sachs disease carrier testing, in which we are down to a molecular level of activity. You can hardly get more discreet than that. At other times, we are working in very general efforts which are, quite notably, unfocused. The whole concept of humans at risk exemplifies this so that you have the exhilaration of very concrete goals on the one hand and the amorphus but humanistic ones on the other.

There were two other examples of the biphasic or divergent elements of prevention cited during this conference. Dr. Tarjan pointed out in his presentation that there is a very different flavor to elements in prevention which are externally applied--for that you could use examples such as obligatory vaccination and, perhaps, newborn screening, and others

which are truly participatory. The dynamic is different there, and he used as examples the utilization of contraception and the application of seat belts.

A third dyad was cited by Jim Gallagher, who indicated that measures which tend to be more accepted by the public and by legislatures are those which primarily affect one specific kind of person. One could use as an instance the employment of phenylalamine-low diets in a newborn with PKU. But there are other measures that affect all of us which are much more controversial; an example would be a change in the deployment of the resources in our culture.

A *fourth* element in prevention policy is that we have still some trouble with numbers and even with concepts. It did not come out in great detail today, but whenever one looks below the covers, if you will, there is a great deal of unrest regarding a matter as simple as incidence, not only incidence in the field as a whole, but incidence in many of the subsets. It has taken me a good many years to appreciate how troubled the numbers are in human variation; therefore it is a fundamental assignment in prevention design to improve our grasp of incidence and prevalence.

The Centers for Disease Control (CDC), under Godfrey Oakley's leadership, cannot give us the answers for areas much larger than Atlanta, which is a little shocking. Dr. Tarjan has spent much of his professional life commenting on this whole business of incidence and, perhaps, in the question period he might give us the latest word, but it certainly is an area that suggests some humility is appropriate as we consider evaluations of our activities.

We also have, as I mentioned, trouble with concepts. There remain, and this was so well brought out by Dr. Mercer, conceptual difficulties with the whole business of intelligence measurement. If any of you did not come away from this conference with the notion that mild mental retardation is a swampland, then you were not listening. I also have had the feeling, as I am sure many of you have had, that the whole area of the social meaning of mental retardation has been only partially explored.

The *fifth* item is the whole business of cost accounting and evaluation. I have traditionally attempted to resist in my presentations, any in-depth consideration of cost effectiveness because I am so troubled by the pitfalls in that equation, but we surely have a motley collection of prices on our efforts. Let me cite a few of them; for example, the presentation of a booklet like this one, which has been distributed by the Massachusetts Department of Public Health. It reads "If there are children in your future know these facts." It is an attempt to bring to young people some additional insights on prevention potentials and it costs six cents. The completion of a PKU test in Massachusetts costs $2.15; a cogenital hypothyroidism test, $2.85. Immunization for rubella costs $9.75. Completion of a hexosaminidase-A measurement to identify a

Tay-Sachs carrier in our program costs $37.50. An amniocentesis with the necessary cytogenetic follow-through varies enormously on how you add it up, but costs perhaps $1,000. And the enrollment of a child with Down's syndrome in a private early intervention program for a year is very handily calculated at 5 percent of the gross family income. That spread of expense from six cents on up suggests how difficult it may be when we approach legislators or others and say we are for prevention and look at all these costs in our Action Agenda. They may freeze.

Regarding evaluation of programs, some good guidelines have been developed, and I am particularly struck by those that were brought forward recently by John Fotheringham from Toronto. He suggested that for each of our programs we ask 11 questions and honestly gather the answers. Then we will be in a position to defend our policies. For example:

1. Do the causes under consideration result in a significant incidence in mental retardation?

2. Do these elements also result in a significant incidence of other handicaps?

3. Does the strategy that you propose reduce the incidence of mental retardation from these causes?

4. Does it reduce the incidence of other handicaps?

5. Is this knowledge known by those who will implement it?

6. Is this strategy generally acceptable?

7. Does this strategy require sustained motivation to be effective?

8. Is there an available delivery system that is widely distributed throughout the population?

9. What is the expense to widely implement the strategy?

10. Is the strategy generally safe?

11. Is the strategy at present widely applied?

I, personally, would view those as the most satisfactory set of analytical criteria to use before you go to the legislature with your Action Agenda.

The *sixth* element in establishing prevention policies requires particular scrutiny when you are in the determination phase and are considering the elements in the broad category of human rights. It is

intriguing because prevention activities in many regards are enormously pro-human; they work for a full realization of human potential. At the same time, we carry along some baggage which is potentially quite threatening. The whole area of registeries, pregnancy interruption, labeling, and allocation of resources comes to mind particularly.

When you are taking prevention on the road, please remember that, first, you have got a movement behind you. Second, there must be a multiplicity of agencies and facilities involved. Remember that there is some peculiar divergence in the programmatic focuses; that we still have some trouble with numbers and concepts; that we must attend on occasion to cost elements and the process of evaluation; and that there must be vigilance regarding human rights.

National Prevention Policy

IV. Lastly, I would like you to consider whether or not activities in prevention in the states have a potential for extension to the national scene, per se.

As Jean Elder said yesterday and will further reinforce in a moment, there is already an enormous federal investment, a richness of contributions that relate to potential success in prevention activities. Particularly notable in this regard are the Title V programs and the Developmental Disabilities programs.

This causes some trouble, however, when one looks at the national scene because there is such a profusion of relevant agencies--National Institute of Child Health and Human Development (NICHD), National Institute of Mental Health (NIMH), Division of Maternal and Child Health (DMCH), Administration on Developmental Disabilities (ADD), the Department of Education, the President's Committee on Mental Retardation, and so forth. Furthermore, there is an enormous spread of voluntary and professional organizations that should be counted as we form that coalition; for example, the American Academy of Pediatrics, Association of Retarded Citizens, the March of Dimes, the American Association of University Affiliated Programs (AAUAP), the Kennedy Foundation, Planned Parenthood, The American Association on Mental Deficiency (AAMD) , and so forth. It is somewhat dazzling.

It is hard to know whether there can be a true bringing together of policies that relate to prevention on the national scene. Elizabeth Boggs has pointed out that there are a number of things that interfere at the present moment with developing a national policy. I hope I quote her correctly when I mention six of them:

1. Regarding the formation of national policy, the real constituency is not aware a policy is needed. The principal proponents of prevention are those who have suffered but will not benefit.

2. The national service system is largely discontinuous. With childhood disabilities, life after adolescence has not been acknowledged in the child-oriented health and education movements, and many federal agencies are involved with only portions of the concern.

3. National collaborations do not necessarily extend to the states, and many of the voluntary and professional organizations that meet in Washington do not provide practical applications at the local level.

4. The documentation of a successful outcome has often been obscure, so the ultimate demonstration of disability prevention may be partial, indirect, or difficult.

5. Ethical dilemmas need to be addressed.

6. There is competition with other public concerns.

It seems to me that in 1983, there is a good potential for a fusion, for example, of the prevention activities of the Association for Retarded Citizens (ARC), the American Association for Mental Deficiency (AAMD), and perhaps the American Association of University-Affiliated Programs (AAUAP). The notion, however, that there would be true federal interagency activity, I would propose, is still a limited reality.

A couple of final thoughts: there are some giant examples in which activity in parts led to effects on the whole. I call your attention to PL94-278, in which the voluntary agencies concerned with certain special genetic diseases each finally got their day. The day did not last as long as one might have hoped, but it was made good in the National Genetic Diseases Services Act.

There is one more example, however, that is more important and this is where I place my mandate for Virginia. Parents who were sorely troubled with the educational offerings that were being provided for their children in Massachusetts (specifically parents within the Greater Boston Association of Retarded Citizens (GBARC), burned the midnight oil for months and years with the considerations they wished to bring to educational reform. They did enormously effective promotional work. They got to all the right places, and in something that I still consider an absolute miracle, Chapter 766 was born in Massachusetts, a local version of the Education for All Handicapped Children's Act. It was implemented in the fall of 1974. At that time, there were only three states which had ongoing provisions for special education of that sort; the other two were

Texas and California. For those who are students of the cultural history of these matters, you will recall that three years later, PL94-142 was born. It is an extremely interesting exercise, very reassuring to us from the other Commonwealth, that when you put the two documents next to each other, you can see that many of the same phrases that were hammered out in Boston to make Chapter 766 arrived in Washington and became the wonder of our modern times, namely PL94-142.

Hence, I am suggesting that where state activities are thoughtfully done, where the homework and presentation elements have been given a particular grace, the results of these works can indeed march to Washington. It would seem to me that the strength I am finding in the Commonwealth of Virginia regarding a resolve for prevention is potentially of that order of magnitude. Speaking as an outlander I would be very grateful to one day be able to recognize that the activities of Virginians of good faith had indeed sustained a major modification of the prevention program of the entire country. Thank you and go for it.

Keynote Panel

Prevention of Developmental Disabilities: Federal Action

by Jean K. Elder, Ph.D., Commissioner
Administration on Developmental Disabilities
Department of Health and Human Services
Washington, D.C.

Good afternoon. I am delighted to have the opportunity to spend some time with you looking at the developmental disabilities program.

At times in all of our lives we need the support of others, either to achieve independence or to maintain a measure of it. For most of us those times are when we are young, temporarily disabled, or very old. Some of us need continuing help because of our disabilities. In this group are persons with developmental disabilities.

As U.S. Commissioner of the Administration on Developmental Disabilities, one of my responsibilities is to develop national priorities for services for persons with developmental disabilities.

In order to place this responsibility in perspective, I wanted to give you some background on the DD program within the Department of Health and Human Services and some legislative history.

In 1980 the Department of Health, Education, and Welfare was reorganized into the Department of Education and the Department of Health and Human Services. The social services aspect of HHS is called the Office of Human Development Services, which oversees Federal expenditures of more than $4 billion for programs administered by four major agencies:

- The Administration on Children, Youth and Families
- The Administration on Aging
- The Administration on Native Americans
- The Administration on Developmental Disabilities

The President's Committee on Mental Retardation is also part of the Office of Human Development Services, although it has a direct

presidential mandate, and a board of 21 citizen members, appointed by the president.

Legislation for the Developmental Disabilities Program was originally enacted in 1963 as the Mental Retardation Facilities Act (PL88-164). This act authorized planning activities and construction of facilities. This law was amended by the Developmental Disabilities and Facilities Construction Act of 1970 (PL91-517) which expanded the target population to include individuals with cerebral palsy, epilepsy and other neurological disorders. It also established State Planning Councils. Public Law 94-103, the 1975 amendments, deleted the construction authority and emphasized advocacy requiring states to establish a Protection and Advocacy System.

The Developmental Disabilities Assistance and Bill of Rights Act (PL95-602) enacted in 1978, introduced the provision of priority services and added the functional definition. Subsequently, the legislation was extended through September 30, 1984, by the Omnibus Budget Reconciliation Act of 1981 (PL97-35).

The mission of the developmental disabilities program as mandated by Public Law 95-602 is to assist states in providing needed services to persons with developmental disabilities in the least restrictive environment possible. Because this involves all services, on a continuing basis, and in many cases over an entire lifetime, ADD and its state counterparts take the approach of gearing their operations around existing operations--generic functions at state and local levels.

Apart from the long-range nature of developmental disabilities, most of the clientele are not in need of any single treatment or service but receive different services or combinations of services at different times in their lives. Thus, the program relies on a wide range of services which could only be made available by tapping many agencies, as well as special kinds of help often obtained from nonprofit groups and business firms.

The DD law provides for the commingling of funds with those other programs--integrating the efforts of both specialized and generic services. The limited money available to the states is used to help fill gaps where services do not exist.

Small sums of money are multiplied through adroit use of ongoing service systems. This multiplying effect is one of the success stories of the DD program. Sometimes referred to as "capacity building," it has involved a long-range process of forming a coalition of consumers, state legislators, state agencies, local governments, providers, and the general public.

The developmental disabilities program is a cooperative venture with the states, which do their own planning, geared to their needs.

The Administration on Developmental Disabilities carries out this mission through the Basic State Grant Program, the Protection and Advocacy System, Special Projects, and the University Affiliated Facilities Program.

The law authorizes grants for the purpose of developing and implementing a comprehensive and continuing plan for a system of services; enhancing the quality of services for DD persons; training specialized personnel for services and research; and developing or demonstrating new or improved techniques for delivery of services.

The Administration on Developmental Disabilities is responsible for the following grants programs:

- *Basic Services:* Formula grants to the states for planning, coordinating, and administering services.

- *Protection and Advocacy:* Formula grants for operating a system to protect and advocate the rights of DD people.

- *Special Projects:* Project grants for projects of regional or national significance, their purpose includes demonstrating improved methods of providing services.

- *University Affiliated Facilities:* Project grants to provide partial support of interdisciplinary training programs for specialized personnel to serve DD people and to provide directly certain services to disabled persons.

Now that I have clarified the extent of ADD's authority, let me describe a priority which will have a very visible effect on the service delivery system.

Over the past three years, we have been able to assess the strengths and weaknesses of the system, to review program directions, and to chart a new course which will result in the development of coordinated community-based services for developmentally disabled adults. Our policies will focus on attaining the complementary goals of greater program authority at the local level and increased program effectiveness.

I asked the inspector general of the Department of Health and Human Services to conduct an assessment on the transition of developmentally disabled youth from school to adult life. From my own experience as a program official at the state level, and now as commissioner at the national level and from my observatons across the nation, I have come to realize that a major shortcoming of our system emerges precisely at this point: developmentally disabled young adults, graduating from the public education system have extremely limited options. The adult service delivery system which was intended to phase developmentally disabled youth from school into day activity centers or sheltered workshops as preparation for their entry into the mainstream of the social and economic life of the community, was in large measure not working. "New graduates" are placed where there are vacancies, regardless of their skill, potential, or interests.

According to the inspector general's study, adult services were not approximating the quality nor the results of the education system. Parents and advocates, as well as handicapped young people themselves, were frequently dismayed and disappointed that the "continuum of services" does not facilitate appropriate movement through services.

While several states have been actively grappling with and resolving this transition problem, most states up to now, have merely viewed it as an emerging issue related to the confluence of three factors:

- Increased parental expectation for appropriate community services;
- Fragmented nature of the existing adult service delivery system;
- Continued limited availability of certain adult services.

Our efforts and our priorities, therefore, will focus on remedying this situation. Our basic aim is to reduce the prevalence of lifetime dependency which presently is the fate of the great majority of developmentally disabled people.

Action I

HHS, with its employment initiative, has already charted first steps to be taken in ensuring that DD individuals appropriately advance through the "continuum of services," as they advance through life. I will direct the departments' efforts, launched by President Reagan on November 28, 1983, as part of the "Decade of the Disabled" (1983-1992).

This nationwide effort will solicit job opportunities from private sector employers and match these openings with developmentally disabled

workers who are presently able or could be readily trained to function in competitive employment. We have set a goal of 25,000 job placements in the first year.

I recognize this is but a small percentage of the 3.9 million developmentally disabled persons in the nation, but it is an impressive beginning. We are truly encouraged by expressions of support from other agencies in the Executive Branch, which has a role in employment for handicapped people, and from consumer organizations and the private sector, which are already major partners in this critical effort.

Action II

Further, we need to deal with the "earnings cap" problem in the Social Security Act, which in effect penalizes handicapped beneficiaries who want to work. Not only do they lose money as they earn dollars in wages, but they concommitantly risk losing important Medicaid benefits when they exceed a specific earned income, roughly $240. We are supporting an extension of the demonstration program, known as Sections 1619 (a) and (b), which permits handicapped beneficiaries to earn nearly $700 a month without losing Medicaid services.

Action III

Still another approach we are taking in addressing this issue is through our Special Projects Discretionary Grants program. In 1983, we funded a project which focused on the transition period from school to the post-school setting, through the development of a model and accompanying training manuals and procedures, that demonstrate ways for direct service and administrative staffs to make the system work for, rather than against, clients in transition. The use of national and well-targeted dissemination channels suggests that this project will have broad impact and utility to diverse audiences concerned with the transition problem. This year, for the first time, we have developed a priority area specifically concerned with the developmentally disabled adult. A major thrust of this area is *the transition period* and calls for studies of, and innovative approaches to, strengthening links between families, service providers, and state and local agencies to assure appropriate placement of developmentally disabled persons and continuity of needed services. Our discretionary grant program provided us with the opportunity and flexibility, through funding, to invite, encourage, and support the contributions of experts and practitioners most knowledgeable in the field to address this here-to-fore seemingly intractable problem.

Action IV

ADD has also funded the UAF networking initiative for services to adults with developmental disabilities. The two basic purposes of the project are to: (1) develop a national perspective on adult service issues for the entire DD field and (2) define an appropriate role for UAFs to expand their current activities in the area of adult services.

We are looking at the three major areas of adult services for individuals with DD in: (1) learning and adjustment, (2) vocational, and (3) residential living. The project will identify and assess the quality programs in each of these areas. Special attention will be given to medical issues and manpower training needs. Eventually, exemplary strategies will be identified as models.

The challenge of the 60's and 70's was to upgrade rights afforded and services provided to the developmentally disabled. Reshaping services and providing them in an effective, efficient, and coordinated manner has become our focus for the 80's.

Society has but one acceptable alternative. We can *only* afford to welcome into the full life of the community the DD citizenry, maximizing their spatial, social, and economic immersion into the mainstream. That lofty goal is not only humane, it is also the superior economic alternative for society. These coordinated initiatives are paving the route for that goal. It is my resolve that government, the private sector, professionals, and associations will interactively produce a significantly superior "continuum of services" for the DD population so that the subset of society thrives within the arms and heart of "the community."

Keynote Panel

Prevention of Developmental Disabilities: Model State Plan

by Robert Guthrie, M.D., Ph.D.
State University of New York at Buffalo
Buffalo, New York

What is it we are trying to prevent here in the Commonwealth of Virginia? I like to use the late Albert Einstein's definition, a kind of relativity theory of mental retardation, that he probably felt most of his friends and neighbors were retarded. In that light, most of us in this room are retarded; it is just a matter of degree. If we think about some of the things we have been talking about at this conference, it becomes apparent that if we remove lead from the environment of our children and alcohol from the fetal environment, a lot of people are going to be less retarded.

My father was a traveling salesman and he would consider Virginia very good territory right now for selling prevention. Dr. Boggs said yesterday that in addition to seven criteria on a transparency of mine that she used, there should be an eighth one. That is, that prevention action is an idea that is timely. Well, this conference has shown how timely prevention is. In 1972, 11 years ago, there was a national meeting of the youth NARC in Pittsburgh. Their theme was prevention. Some of the young people, high school and university age, hitchhiked across the country to the conference. This button I am wearing, "To our children's children," came from that conference. We probably had about 10,000 of those buttons made at Fort Erie, Ontario, by the Sheltered Workshop for the Retarded. It is a very popular button, not only with pediatricians and geneticists, but also with their wives. If we are going to dedicate the kind of conference we have here to anybody, that slogan would probably be a good dedication.

The President's Committee that has been mentioned here has been led by Mr. Fred Krause for some 14 years. He said something which I think is very germane to this conference, that the 1960s in the mental retardation movement was the decade of legislation, the 1970s was the decade of the rights movement, and the 1980s is the decade of prevention. I think he is right. If you consider what has happened in the last 25 or 30 years, the attention that is being given prevention is a maturing of that process.

The many people who are parents of the developmentally disabled, as I am, have seen with considerable interest the growth and maturity of private and public organizations concerned with developmental disabilities and mental retardation. We have seen that those tremendous budgetary figures which were referred to by Jean Elder are the result, first of legislation and of the rights movement which required the implementation of legislation of the 1960s with large amounts of public funds. As those costs have gone up tremendously, I think that elected officials may begin to worry about the problem of prevention of lifelong developmental disabilities.

In our approach toward health, we are forced to grapple with the infant who lives rather than the infant who dies. I spent 12 years in cancer research focused on acute leukemia in childhood. We used to often make the comparison between the child who died of acute leukemia and the child who lived with mental retardation. We have come a long way, and this Virginia conference, in more ways than I can express, shows the maturation of our attitudes. The most responsible thing anyone who is concerned with mental retardation can do is to be interested in trying to prevent its happening in anyone else.

Mrs. Maureen Young, who is with the Illinois ARC, and I were asked by the President's Committee some time ago to produce something called a model state plan. I am going to go through this model state plan; bear in mind that the elegant language and the thoughtful way it is presented is not mine, it is Maureen Young's. I would not do her justice if I tried to give it in any other way, so I am going to read it.

Blueprint for Individual States

Because the case for prevention of developmental disabilities is compelling, several states have requested leadership and guidance from the President's Committee on Mental Retardation (PCMR) for developing comprehensive prevention programs. The PCMR believes that a model state plan for prevention based upon the research and experience described above [and that refers to my part of it, the biomedical things, mostly], can serve as a blueprint for individual states to use in drawing up effective and appropriate plans. The diverse nature of the 50 states precludes the drafting of one prevention plan idea for all; however, there are certain characteristics, processes, and programs intrinsic to a model state prevention plan. Implementation of these elements within a particular state will and should reflect the unique resources and needs of that state. Characteristics of the state which are relative to a model plan include demographic and geographic features, political organization, epidemilogical data, economic conditions, availability and accessibility of research and service resources, strength of consumer organizations, and other factors such as involvement in federal, regional, or centralized prevention efforts.

The structure of a model state plan. The model plan work group of the President's Committee on Mental Retardation's National Prevention Showcase and Forum in Atlanta determined that although there are differences in the characteristics of states, one can identify essential components of a model state plan for prevention which are consistent from state to state. These components include the following activities which are listed on this transparency:

1. We consider the establishment of state commissions for prevention a keystone of the plan

[A bill in New York state has been introduced on such a commission based on the governor's action plan. I do not know whether it will be passed, because state commissions are very unpopular. They seem to live forever and they take money, but this, I think, is important for the interagency coordination that has been talked about here. Maybe there are other ways that are just as effective, but Maureen and I do not know of any better way.]

2. Gathering a state's specific demographic and epidemiological data related to the causes and incidences of mental retardation and comparison of this data to national figures

3. Estimation of cost

4. Development of funding mechanisms

5. Integration of prevention into the existing service delivery system

6. Coordination of private and public sector prevention activities

7. Involvement of consumers at all phases of prevention planning and implementation

The Golden Twenty

Now these seven activities provide the structural support for a state prevention action plan and set the stage for states' specific needs assessment and program development. With a planning structure firmly in place, selection of program goals and methods can begin. Program design assumes knowledge of ways to prevent mental retardation. Dr. Allen Crocker's "Golden Twenty" characterizes the basic elements of a comprehensive prevention program under the headings of primary, secondary, and tertiary prevention. Primary prevention is defined as prevention of a condition among the general population. Secondary prevention focuses on a group known to be at risk for the condition, and tertiary prevention seeks to ameliorate the effects of that condition among those who have it. The

20 elements which Crocker believes essential to a good prevention program follow: primary--rubella immunization, prenatal care, special care of prematures, genetic counseling, advice concerning alcohol intake during pregnancy, a reduction of exposure to lead, prevention of kernicterus, reduction in childhood accidents, reduction of teenage pregnancy, efforts to decrease child neglect and abuse, health and nutrition education; secondary--screening of newborns treatable metabolism problems, screening for hypothyroidism, amniocentesis for older mothers, screening for elevated alpha fetal protein level, and identification of carriers of genetic conditions related to retardation; and tertiary--early intervention and stimulation, continuing provision of services to families with children with disabilities, continuing research regarding causes of retardation, and education of physicians and other professionals.

Dr. Crocker's "Golden Twenty" represents many different causes, target groups, and actions. By focusing on target groups and actions, the New York Governor's Conference for the Prevention of Developmental Disabilities/Infant Mortality has identified seven action areas:

1. Public education and information

2. Prevention services, maternal and infant health

3. Services to populations with special needs

4. Education for special groups

5. Service coordination and integration

6. Data and research for planning and evaluation

7. Implementation

For each of the topic areas, the New York conference proposes a goal, one or more objectives, and specific activities. Prevention planning documents exist within other states; i.e., Illinois has published *Prevention of DD in Illinois, Options to Guide State Prevention Efforts.* Many of the elements of a comprehensive plan are included in the state health department's maternal and child health plans. Other components can be found in state public aid or child welfare mandates. The 11-point model state plan which follows is a synthesis of Dr. Crocker's "Golden Twenty," New York's prevention action plan, the Illinois option to guide state prevention efforts, previous PCMR reports, and the recommendation of the PCMR model state plan work group from Atlanta.

In the model state plan, the programs allow for regional differences in needs and resources and welcome a diversity of program priorities and activities among the states. The President's Committee of MR believes that each state plan should address these 11 points in its program for prevention of MR:

1. Public education
2. Maternal and child health preventive health services
3. Nutrition programs
4. Environmental protection
5. Genetic services
6. Newborn screening programs
7. Developmental screening
8. Coordination of prevention services
9. Citizens' advisory groups
10. Research and evaluation
11. Legislation

Public Education

Under public education, both the general public and specific groups within the public need basic information about the importance of medical care, nutrition, safety, and education for optimal child development. Groups requiring education oriented to their needs and societal roles include not only adolescents and parents, but also service providers, teachers, policy makers, government officials, legislators, and the media. In other words, all persons responsible for the health and well-being of children need general and specific information about prevention of MR. This information should include the why, how, and what of a specific prevention measure. For example, in the area of child passenger safety, a public education campaign should alert adults and older children to the importance of car seats and seat belts, should demonstrate the proper use of such equipment, and should identify resources for locating the proper equipment.

I was struck that Dr. Lorne Garrettson yesterday commented on the fact that educational programs in general, in his experience, all fail. Legislation works. The old saying, there is nothing like a law to educate, is important.

Similarily, in the area of immunization, parents should understand that childhood diseases are dangerous and that shots which can prevent many illnesses are available through private physicians, clinics, or hospitals. A comprehensive public education plan should address child

health and safety and adolescent and adult reproductive health. As in any marketing campaign, the specific content and style of the education approach should be tailored to the unique needs of the target groups. I am thinking of Mrs. Sara Litch and her unique educational curriculum, 700 pages of material for teachers of adolescents in junior and senior high school, which has been so successful and has been adopted in several states.

Information on reproductive health would be presented differently to adolescents than to adults. Education of legislators about a pending newborn screening bill should take a different shape than education of hospital administrators or parents. I was impressed with the marketing chapter in this book from Virignia because marketing is so important and has been neglected. Attitudinal changes are absolutely essential for prevention.

Public education stands as a separate program in a model state plan and is a factor in the implementation of each of the other 10 points. Informed consumers, policy makers, administrators, and care givers are essential to the prevention of MR.

Maternal and child preventive services and the provision of a high quality prenatal, obstetrical, and neonatal care during the first year of life can reduce a newborn's risk of illness and death. Of particular concern are adolescents whose infants experience a high degree of low birthweight and whose health problems should be addressed in a broad context, taking into account social and psychological considerations. *Objectives for the Nation,* the federal document promoting health and preventing disease, lists 13 specific measures to improve the health status and reduce risk factors for women and young children. These include family planning, prenatal care, innovative multidisciplinary medical care systems, accessible services, regionalization of perinatal services, adequate linkages, outreach, evaluation of quality of perinatal and infant care, identification and tracking of infants and families with specific problems, reduction in teenage and other high risk pregnancies, elimination of unnecessary radiation exposure, adequate primary care, and support groups for parents of high risk infants and other parents under stress. Another important facet of a maternal and child health service is primary care for children beyond the first year of life through adolescence, including an immunization and screening program. Genetic and newborn screening programs, because of their specific relevance to prevention of MR, are discussed separately in this document.

Nutrition Programs

Under nutrition programs, Winston Churchill said "There is no finer investment for any community than putting milk into babies." Participation in federally supported food programs, including WIC (Women, Infants

and Children), school lunch, and Headstart, should be expanded. That is a challenge to take back to Washington. Nutrition education, along with the means for obtaining an appropriate diet, is also critical because nutritional status can combine with other causes of MR, such as lead poisoning or alcohol, to increase the risk of brain damage. It is essential that children who are at nutritional risk be identified and supplied appropriate diets. Dietary supplements for children with inborn errors of metabolism, vitamins and calcium for pregnant and lactating women, and balanced diets for all children are but a few of the specific nutritional services the state can support.

The list of substances known to cause reproductive, neurologic, or other damages which can produce MR is long and growing every day. Enforcement of existing enviromental legislation, screening of women and children for undue absorption of toxic substances, corrections of hazards where they are known to exist, require coordinated effort on the part of the administrative and regulatory agencies of the state and federal government. Specific actions which can reduce MR include such practices as annual screening of all children ages 1 through 6 years for lead absorption with appropriate medical and environmental corrections. Annual screening for blood lead levels should be included in any state plan for prevention. This is actually the recommendation from the Maternal and Child Health Service; a memo from the assistant surgeon general went to all the states 15 months ago. Bear in mind that was what was the right hand recommended, while the left hand just cut the funds by 25 percent.

Massachusetts is almost unique, not only by legislating that lead be taken out of rum as was advised by Ben Franklin 200 years ago, but also by having a law on the books since 1972 that says all children should be screened. Massachusetts does screen 85 percent of all the preschool children in the Boston area. It screens 25 percent of all the children across the state, so that is a model state plan on lead screening, although it is not doing enough because, you see, the federal government wants all children screened.

Genetic Services

Counseling couples at risk before they have any children, counseling before the fact, should be the major goal of any genetic prevention program. That is from the book that was published by the PCMR on prevention strategies at work, page 3. In its 1980 report to the president, "Mental Retardation Prevention Strategies That Work," the PCMR identified five ways to prevent MR caused by genetic factors: counseling for individuals at risk of having a retarded child; screening for metabolic disorders; screening of the normal population to identify carriers of genetic disorders; prenatal, that is, fetal diagnosis of genetic disorders; and early treatment of such disorders. Newborn screening and early treatment programs are discussed elsewhere. Screening of the general population, testing and counseling, and follow-up services

for persons at risk are often concentrated in large urban areas with university hospital resources. Expansion of existing programs and increased accessibility of genetic services ought to be addresssed in any state prevention plan. If resources allow, the plan might also include support for genetic research. Incidentally, one-third of the money for genetics in the province of Quebec has always been dedicated to research and development, two-thirds for services.

Newborn Screening Programs

Quoting Dr. Richard Koch, "In California there has not been a single PKU person admitted to our state institutions who was born after 1966, the year our screening program began." But the PKU test was produced 22 years ago; a lot of things have been done lately. PKU, hypothyroidism, gallactosemia, and other inborn errors in metabolism lead to MR unless detected early in infancy and treated with appropriate diets. But only half of the newborns in the U.S. are screened for galactosemia, and that has been detectable for as long as PKU and it is much simpler to treat. It is rare, one in 50,000 (PKU is one in 12,000 in this country); and it is so simple to treat--you just avoid galactose in food entirely. Centralized screening of all newborns has proven to be an effective prevention technique. Where screening is done by a variety of laboratories, costs rise and efficiency decreases. In those areas of the country, such as the New England and Northwestern states, where regional metabolic screening programs have been formed, there has been not only an increase in efficiency and reduction of costs, but also an increase in the number of children screened. types of disorders screened for, and subsequent prevention of MR. There are now four multistate regions. The first state to send specimens across its borders to another state was Montana, and it had to change the state constitution. That was largely due, I think, to a woman who was the exective director of the Montana ARC whose child was retarded because of hypothroidism. The availability of that test has led to a good deal of regionalization.

Several states have established networks and/or regional centers to advise parents and physicians on dietary treatment and other supports necessary for children with metabolic disorders. Often in the legislation of the 40-some states that now have laws, the follow-up was forgotten. You just had to screen the children. Each state plan should include a mechanism, whether internal or cooperative with other states, or a combination thereof, which provides screening, dietary supplements, medical care, and counseling necessary for children with metabolic disorders.

Medicaid eligible children are provided developmental screening though the federal early and periodic screening diagnois treatment (EPSDT). EPSDT-type programs should be expanded to all children in the state, regardless of income level, with children diagnosed as developmentally at risk, delayed, or disabled provided with the appropriate early intervention program.

The services described above cut across traditional socioeconomic and political boundaries. The state agency with responsibility for coordination of the overall prevention plan must design service plans and allocate resources in order to assure accessibility for all state residents. In some states, a prevention circuit may be designed with interdisciplinary teams providing services on a frequent schedule in rural communities. This has been done by some of the university-affiliated facilities which have a traveling team that visits the community on a regular basis. Other states may arrange a transportation system to bring the patients in to the facilities. The unique characteristics of the state combined with other statewide programs can suggest a solution of accessibility problems.

An advisory group on the implementation of prevention programs can ensure that the state's prevention programs are meeting the needs of the population. Designated state agencies are cooperating with each other and with consumer and private sector service providers. A state advisory group for prevention ought to be established. Perhaps some type of legislative commission will be necessary to provide that function. This group should be composed of individuals and agency representatives reflective of the demographics and resources of the particular state. The group should be charged with a watchdog function to ensure interprogram communication and coordination of services and to address specific programs as they arise. This group might be a part of the commission on prevention or a separate entity with representation on the commission.

Research and evaluation, a specific state program, office, or agency, should be given responsibility and held accountable for coordinating prevention research and evaluation within the state. Dr. Hickman in California has been appointed the prevention person. Each state should gather and disseminate demographic and epidemiological data about MR, philosophically and financially support basic research programs in fetal development, undertake applied research on the effectiveness of specific prevention strategies, and study the cost-benefit ratio of the various prevention initiatives. For example, the General Accounting Office of the United States, in a report to Congress in 1977, included the statement that 2,500 accountants who were watchdogs for government money found that if the U.S. government invested $18 million a year in screening all 3.2 million infants in the country for seven conditions, the goverment would save over $400 million, a 20-to-1 cost benefit. That is what Japan is doing. They have a different administration over there.

Some states may find that these efforts can best be handled through regional research programs supported by two or more neighboring states. In every instance, however, specific state agencies are subcontractors responsible for a component of the overall prevention plan and must provide for an evaluation component for their areas of responsibility.

Finally, the research and evaluation office should communicate program results and new knowledge to appropriate agencies, individuals, and the general public in a timely and suitable fashion. The new information developed through experience and research will strengthen the foundation of both the public education program and the public education initiatives of the varied components of a model state plan for prevention.

Remember that there is nothing like a law to educate. I think that is important. Prevention of disabilities can often be addressed most effectively through legislation or regulation. Mandatory immunization of children, use of child passenger restraints, removal of lead from household paint, newborn screening, and other prevention measures have, in many states, contributed to a decrease in certain types of MR. Each state should develop a mechanism for the consideration of prevention legislation as part of the ordinary business of the state. Prevention is not a single issue, but a complex blend of medical, social, educational, and economic concerns. Prevention needs to join highways, schools, and natural resources as a perennial legislative concern. A state with a demonstrated commitment to prevention of disabilities can take pride in its values and accomplishments.

Coordinated Prevention Services

Next, let us deal with priorities. A comprehensive state plan for prevention will necessitate choices because you want to begin with action that is successful. The Western New York Task Force on Prevention of DD has developed seven criteria for prevention action to assist in prevention program development. These criteria are as follows:

1. *The cause of the DD and the means of prevention should be well understood; i.e., injuries from car crashes are a leading cause of brain damage and use of child passenger safety restraints can frequently prevent injury.* Did any of you ever think about why a baby's head gets so big? It's because the brain is growing so fast. Dobbing estimates that the brain, at its peak, is growing 2 milligrams per minute in weight of protein, and, of course, the child is very vulnerable physically, as well as in terms of growth activity, because a growing biological system is always more vulnerable to any kind of agent.

2. *A significant number of cases is detected.* Car crashes are a leading cause of death and serious injury for children. That example is mute because Virginia is already doing something about it. In other instances, such as PKU, which affects approximately one in 15,000 babies, the number becomes significant when considered in the light of human economic cost. Lifetime care for one child with PKU can cost the state an estimated $1

million. I should mention that I have been involved in 25 different malpractice suits, so far, of children who were missed, and $1 million is the lowest figure. These cases are always won by the plaintiff.

3. *The cost is reasonable.* Some prevention methods, such as newborn screening, lead screening, and immunizations are relatively inexpensive. For some families, however, $40 to $50 for a child passenger safety seat may seem like an unreasonable sum of money; however, not to the insurance company. One insurance company alone in Michigan has given away 7,000 car seats to its customers because it knows it will save money in medical claims. When balanced against the risk of injury and the cost of medical and supportive care for an injured child, however, the cost has to be reasonable and the cooperation of the public and the professionals is likely.

4. *Cooperation of the public and professionals is likely; little controversy is expected.* Lest the many noncontroversial prevention activities described here and elsewhere become lost in the chasm between polarized groups, state prevention programs should exercise caution before embarking on controversial projects. Value judgments will be made in any prevention program; these judgments, however, should reflect sensitivity to the democratic and pluralistic society for whom the state exists.

5. *A definite gap in services exists.* Some states have no newborn screening program, others have comprehensive programs, and some fall in between. A state which screens for 12 metabolic disorders may turn to issues such as genetic research, whereas a state with little or no screening program may assign this as top priority.

6. *Model programs exist.* Although some states will want to develop model programs and are encouraged to do so, a newly formed state prevention program should begin with proven models. For the prevention initiative to survive and flourish, early success is crucial. Furthermore, replicaton or adaptation of a successful model is generally less expensive than the development of a new model.

7. *It will be possible to measure success.* In a comprehensive state plan for prevention many components need to coalesce and function effectively. Success can be measured in terms of both the structure and the effectiveness of the plan and its objectives. For example, structural success may include the formation of a legislative commission for prevention or the signing of an interagency or interstate cooperative agreement. Effectiveness

of prevention programs can be measured in the short-term for such activities as newborn screening (the annual number of PKU children identified early and treated effectively) or the long-term (the incidence of mental retardation among the children of parents who received targeted prevention education as adolescents, compared to the general population.

Prevention Program Criteria

A model state plan for prevention coordinates human, economic, and social resources in a thoughful process of identification of causes and prevention of mental retardation and a systematic application of that knowledge through a variety of approaches.

Systems approaches suggest that "everything is connected to everything else." In this connection, a program, by definition, should be a planned effort to approach various aspects of an identified major problem by means of a series of interrelated projects; a single, isolated, one-shot project is not a program. This definition of program connotes a *sustained commitment* consistent with planned social change in order to modify institutions to make them more responsive to community need.

A "sustained commitment" is the cornerstone of a model state plan for prevention. The meshing of effort and services demanded of comprehensive prevention planning requires the support of both the executive and legislative branches of government.

I forgot to cite John Fothingham's book, *Prevention of Intellectual Handicaps,* published by the Ontario Association of the Mentally Retarded.

PREVENTION IN VIRGINIA

by Governor Charles S. Robb

It is a pleasure for me to join you today at this 1983 Virginia Mental Retardation and Developmental Disabilities Prevention Conference. As you know, one of my first tasks as governor was to re-enter the federal program. You will remember also that the report of the Commission on Mental Health and Mental Retardation to the governor and the General Assembly in 1980, which was chaired by Delegate Dick Bagley, emphasized the importance of prevention when it requested that "the Secretary of Human Resources establish as a high priority the initiation and coordination of programs for prevention and public awareness of mental disabilities among state and local human service agencies."

I looked forward to joining you here today because I have followed with interest the plans for this conference as they have developed and unfolded over many months. I would also like to thank the conference sponsors, the Virginia Department of Mental Health and Mental Retardation, the Association for Retarded Citizens of Virginia, the Developmental Disabilities Planning Council, and Virginia Commonwealth University, for their efforts in bringing together the impressive professional talent and dedication assembled here. I know that the representatives of these organizations and others have worked hard to develop the excellent program for this conference and to put together the Action Agenda for the prevention of mental retardation and developmental disabilities in Virginia. This document, which I have reviewed in its original draft version, and which you are now refining, represents what I believe to be the best thinking of the most knowledgeable Virginians and of many other people from across the country, as to the steps we can take now to strengthen the prospects of prevention of developmental disabilities. The development of this Action Agenda coinciding with this conference means that tomorrow afternoon, after all of the speeches have been given and all of the papers presented and you all return to laboratories, to classrooms, and to community service centers around the Commonwealth, the ideas you have shared and the work you have done here will represent a beginning rather than an end. Because the Action Agenda for Prevention will guide both your efforts and mine over the next few years as we join in a common effort to combat the conditions that can lead to mental retardation and developmental disability.

Moreover, in what we are beginning here, we are building on a solid foundation, for Virginia has much to be proud of in its preventive efforts in the field of mental retardation. In 1976, the Committee to Study the Preventable Causes of Mental Retardation reported to the governor and the

General Assembly on the crucial need for greater public commitment to, and state support for, efforts aimed at prevention. This early initiative to direct and coordinate state policy toward the prevention of mental disabilities led to the identification and involvement of a number of interest groups and leaders in the field of prevention who have worked together to identify goals and strategies for Virginia to pursue.

Virginia Birth Defects Registry

Many of you who are here in this room, of course, were instrumental in sponsoring the conference on the prevention of developmental disabilities that was held in Richmo in 1979. As most of you know, Dr. Howard Sparks, who is serving as the chairman of this conference, led a group called the "pilot committee," which identified the themes and issues developed at that 1979 conference. He, along with many others, has worked to enlarge upon those themes over the succeeding years. During those years, Virginia Developmental Disabilities Planning Council has worked to translate those ideas into practice by promoting prevention activities at both the state and local levels. In 1980, the Council awarded two grants for programs to advance the cause of mental retardation. One, the Virginia Birth Defects Registry was begun at the Medical College of Virginia. The Virginia Birth Defects Registry, helps us to identify and keep in touch with those children who are born with identifiable handicapping conditions or developmental defects at birth--the very children who might benefit from services sooner, and whose families might be spared a future pain if they take advantage of the available genetic counseling services coordinated as a result of the Birth Defects Registry.

The second grant was awarded to encourage greater local interest in and an understanding of exactly what mental retardation and developmental disabilties are, with a complimentary emphasis on training interested people in prevention methods in communities throughout Virginia. That grant, awarded to the Region Ten Community Services Board in Charlottesville, resulted in the preparation of training materials and manuals for communities to use in forming prevention coalitions. In these coalitions, state and local agencies and private groups or individuals cooperate by combining their resources to educate the public about things that people can do to reduce the risk of having a child with mental disability. That project has developed nearly 15 community coalitions throughout Virginia, which work to educate the public about the importance of receiving early and thorough prenatal care, avoiding the use of drugs and alcohol while pregnant, using proper auto safey seat restraints for young children, and so on.

Prevention Efforts at State Level

At the state level, the growing emphasis on prevention has led to

important developments. Among the many things it accomplished during the last session, the General Assembly was particularly successful in the progress it made in developmental disabilities. In a law which became effective on January 1, 1983, the Virginia General Assembly stipulated that all children under the age of 4 be restrained in an approved auto safety restraint system. More than 150,000 children under the age of 14 suffer disabling injuries in automobile accidents in the United States each year. As many as 15,000 of these children may suffer mental retardation as the direct result of head injuries in crashes--and 80 percent of these disabling injuries could be prevented through the simple use of seat restraints. This needless loss of life and health can be prevented. And, as you all know, the law helps those who cannot afford safety seats by providing the seats, free, through a program partially funded by the fines paid by offenders. I am delighted to know that the partnership of state and local activities with the private sector has been most effective in this area and that many of Virginia's coalitions to prevent mental retardation have organized car safety seat programs.

In addition, during the 1983 session, the General Assembly passed, and I signed, a bill which augments Virginia's newborn screening program in the search to identify early, very rare but very serious, metabolic disorders. For reasons both linguisitic and physiological, it is a good thing that they are rare because they are nearly impossible to pronounce: galactosemia, homosistenuria, hypothyroidism and maple sugar urine disease. These diseases occur with almost miniscule frequency in some cases--one in every 250,000 births. But, if not identified and treated, these serious disorders can cause severe forms of mental retardation and other--life threatening handicaps.

If, however, we can identify these conditions before birth, at birth, or shortly thereafter, we can correct them through sustained special diets, thereby preventing the metabolic imbalances which result in brain damage and severe disabilities and, in fact, completely prevent the onset of any handicapping condition. As rare as these conditions are--and taken together we might predict only one or two births every year or two--the small cost of this screening program can easily be justified if we are able to identify and prevent even a few handicapping conditions. If untreated, these conditions could result in a cost to the Commonwealth of up to $20,000 per child per year for indefinite intensive care and treatment. Even more important, of course, than a good return on our investment of dollars is a good return on our investment in human potential and well-being.

We can take pride, I think, in the fact that Virginia, through our Department of Health, has a metabolic screening program which ranks among the best in the country. At each center, doctors, nurses, and scientists are fitting together the thousands of pieces of the puzzles in genetics and in maternal and child health care, which will eventually lead to the identification and prevention of more causes of developmental disabilities. We know now that there are well over 250 to 300 causes of

developmental disabilities that have been identified. We know, too, that there are not, and will not be, any magic or major break-throughs which in one grand progressive stroke eliminate the conditions which cause these disabilities. It may frustrate many to know that our job is difficult, but it encourages me to see how many of you are working so hard toward achieving those significant results.

It seems to me that this conference demonstrates the positive aspects of interested professionals, community leaders, and consumers working together to solve problems that require broad coordinated efforts. It reflects the inspired approach identified by the late President Kennedy, for whom mental retardation was a concern prompted by the immediacy of family reality. In a special message to congress in 1963 he said:

> "Prevention is far more desirable for all concerned . . . [but] will require both selected specific programs directed especially at known causes, and the general strengthening of our fundamental community, social welfare, and educational programs which can do much to eliminate or correct the harsh environmental conditions which often are associated with mental retardation . . . ."

As we continue to work to prevent developmental disabilities, there is one important point which we must never lose sight of--we aim to prevent developmental disabilities, but that does not mean that we do not value disabled persons. All of the people serving with me in this administration feel as deeply as you do that the rights to dignity, respect, and a rewarding life of citizenship for men and women with disabilities are as sacred and inviolable as those of any other of our citizens. Nothing in our commitment to the prevention of disabilities detracts from our commitment to address the needs and problems of persons who have these disabilities. In this respect we are like physicians, who seek a cure, even while sparing no effort to provide treatment.

The plan you are developing is both thoughtful and hopeful. Not everthing the Action Agenda will call for is possible today. Not only are we in need of more knowledge about the causes of developmental disabilities, but obviously we will need more money than is likely to be available. But now is not the time to point out what we cannot do, but what we can do. What we in the executive branch of state government, the state agencies, and the General Assembly can look to you for is what can and ought to be done now.

I am confident that you will pursue this objective vigorously. I welcome that, and I look forward to working with you. For Virginia's children, and for their children, I thank you.

Conference Candids

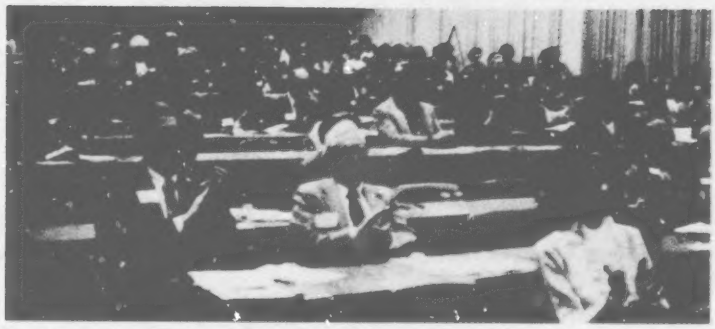
Which one's the speaker?

(Left to right) Dr. Elouise Jackson, Dr. Philip Markowitz, and Dr. James J. Gallagher served as panel speakers in the workshop.

Enthusiasm was high as over 400 people from across the country attended the "Action for Prevention" conference.

Healthy babies just don't happen . . . we make them happen!

(Left to right) Speakers James Windsor, Robert Steig, and Marianne Cashatt chat between presentations.



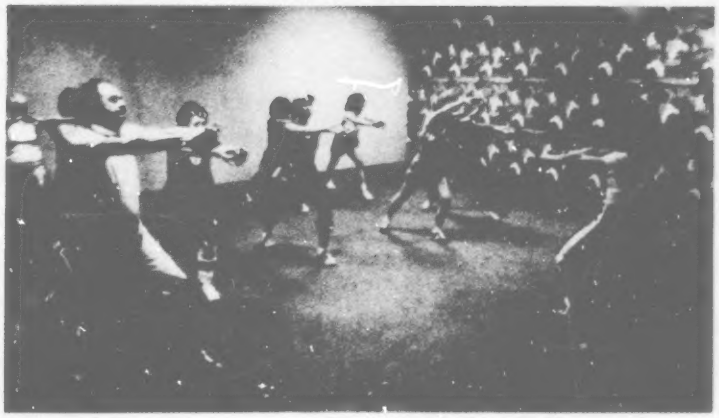
Conference attendees listened to workshop discussions with Virginia's Action Agenda in mind.

Earl and Marion Agee try to choose among the 17 scheduled workshops.

(Left to right) Commissioner of Mental Health/ Mental Retardation Joseph Bevilacqua, Dr. Ruth Diggs, Governor Charles Robb, and Conference Chairman Howard L. Sparks smile for the camera.

Charles Osterhoudt and Marcia Penn practice the lighter side of prevention—humor.

Conference participants stay fit in an evening aerobics exercise session.



Workshop Discussions

On December 15, 1983, forty speakers presented papers in sixteen workshops covering the range of preventable causes of mental retardation and other developmental disabilities. Respected practioners from the fields of special education, medicine, early childhood education, genetics, sociology, psychiatry, and perinatology spoke as did individuals whose knowledge of developmental disabilities came of close, personal experience. Current research findings, effective preventive strategies, and considerations of an ethical, social, and economic nature were discussed. Tapes of individual workshops are available from Child Care Information Center in Hampton, Virginia, thanks to the kind assistance of James Chenault and George Scott. Due to space limitations, only summaries of the workshops appear below.

Ideal Components of a Statewide Genetic Services Program

by R. Steven S. Amato, M.D., Ph.D.

Ideally, genetic services:

1. Should be integrated into every physician's practice
2. Should be integrated into the state's health care delivery and educational systems
3. Should include a method of identifying children and adults ascertained for genetic disease so that assessment, and, if needed, intervention, can begin as soon as possible.

By careful thought, all physicians can integrate genetic awareness into patient care by telling family members whether or not the disease is hereditary and, if so, what risks of recurrence exist. The patient and family should also be informed about the disease, mode of inheritance, possibility of prenatal diagnosis, prognosis, and treatment options.

It is important that all physicians be able to recognize genetic conditions to refer patients for appropriate and prompt treatment.

Comprehensive genetic care requires respectful partnerships between physicians, nurses, dieticians, teachers, health departments, and volunteers.

We will never prevent all birth defects from occurring, but much can be done through early intervention and counseling to diminish the effect of genetic disease on the patient and family.

Role of a Birth Defects Registry

by Linda A. Corey, Ph.D.

A birth defects registry can serve as a valuable epidemiologic tool which can provide incidence and prevalence figures for a given population, can pinpoint areas in the community where genetic services are underutilized, and identify areas in need of educational programs.

The Virginia Birth Defects Registry was established in 1981 as a pilot project with grant funds provided by the Developmental Disabilities Unit of the Department of Mental Health and Mental Retardation.

The registry's three goals were:

- To collect information from birth records relevant to the incidence and prevalence of congenital malformations in Virginia.
- To provide and maintain a coordinated system of genetic case identification referral.
- To establish an outreach program which would make the availability of genetic services known to all in need of them.

To date, complete demographic information has been entered into the registry on 1,539 individuals with reported congential malformations born between January 1, 1980 and December 31, 1982. Complete information for 1982 is available only for children born with neural tube defects, due to changes in the interpretation of current privacy laws.

A registry can also help:

- Provide information useful in planning the type and magnitude of services for the developmentally disabled.
- Pinpoint areas in need of genetic education and services.
- Provide important information regarding the existence of clusters of specific disabling conditions or genetic disorders which may indicate a mutagenic agent in the environment.

- Serve as a respository for information concerning the existence of other affected individuals in families seeking genetic counseling.

Current Status in Virginia

by Thaddeus E. Kelly, M.D., Ph.D.

Congress passed the Genetic Disease Act in the mid-1970s. In 1978, Virginia became one of the first states to receive federal funds under this legislation. The Genetic Disease Act mandated statewide coordination of genetic services, which were to be organized under the State Health Department. Federal funding lasted only four years, but has been picked up effectively by the state since then. With the network of genetic service centers established by the act in place, we are able to do a great deal more than we could earlier.

I will review the current status of genetic services in Virginia by briefly discussing where we stand with regard to each of Dr. Oakley's items on the list of comprehensive genetic services:

1. *Newborn Screening:* Virginia screens for PKU and hypothyroidism now. We will begin screening for galactosemia, maple syrup urine disease, and homocystinuria next July under legislation passed last year.

2. *Genetic Counseling for High-Risk Families:* This has been organized in two ways here in Virginia: first, as a response to families who seek genetic counseling through the three genetic centers at the medical schools or satellite clinics across the state. Secondly, genetics professionals from the clinics seek out identified high-risk populations, e.g., residents of the state's training schools, to provide genetic services to affected individuals and their families.

3. *Prenatal Diagnosis for Women Over Age 35:* Approximately 25 percent of all pregnant women over 35 in Virginia are seeking prenatal diagnosis. One difficulty in obtaining an accurate assessment of numbers of persons using genetic services is the fact that many Virginians seek genetic services in neighboring states. There is no existing mechanism for identifying those individuals so we may have an underestimation of genetic services

usage in Virginia. Our services are not as widely used by the rural and nonwhite residents of the state as we would like.

4. *Access to Alphafetoprotein Screening:* Norfolk has developed one of the best AFP labs around. There are many logistical problems involved in establishing an AFP screening program. This is the type of service Virginia should be starting on a pilot basis. The capability is there, but we still need funds to finance such a program and a mechanism for providing statewide service.

5. *Rh Program:* It is not clear if Virginia has statewide surveillance or monitoring of the effectiveness of prevention of Rhesus isoimmunization. This has been left largely to practicing obstetricians.
6. *Tay-Sachs Screening:* The genetics clinic at the University of Virginia provides this service for the state. Due to the relatively small residual Jewish population in Virginia, this service is easily handled from one central location.

To improve the provision of genetic service in Virginia, we must turn our attention to other, less easily defined tasks. A primary need is education of those individuals who need and may benefit from genetic services so they will become aware of both the benefits and availability of genetic services. Future prevention of mental retardation does not depend so much on new research to find preventive techniques as it does on the sound application of those methods we already know to be effective.

Reactions to Other Presentations

by Godfrey P. Oakley, M.D.

As Dr. Corey has shown, a birth defects registry can be useful in a number of ways. In France, the establishment of a registry led to the discovery of a previously unknown genetic disorder.

It is difficult to ensure 100 percent confidentiality. One must weigh the potential benefits against the relatively minimal risks associated with loss of confidentiality.

Workshop: Statewide Perinatal Care Services

Perinatal Regionalization: Its Ingredients, Effects and Development

by Gordon B. Avery, M.D., Ph.D.

Regionalization of perinatal care has had positive outcomes for high-risk pregnancies as evidence from Sweden and other Scandinavian countries indicates. We must create a system to care for mothers and babies in this country, and we must recognize that we cannot have all specializations at all hospitals. Of every 1,000 pregnancies, there will be approximately 90 newborns with medical problems--approximately 68 infants will die, 18 will develop normally, 4 will have major handicaps. We must have a system in place so that the most seriously ill infants can receive proper care.

We should regionalize because:

1. It works.

2. It is too expensive to have critical care facilities in every hospital.

3. There are secondary gains such as research, teaching of uniformity/styles that work best in caring for newborns, outreach and inservice training for hospital staff, community services, and families.

4. More accurate statistics can be kept; each infant can be assigned to the hospital at which it is born.

It is possible, although not with complete accuracy, to identify high-risk and low-risk pregnancies. Best results for high-risk mothers are obtained when they are identified early, receive excellent prenatal care, and deliver at centers established for such high-risk patients and their infants. It is much easier and safer to transport high-risk pregnant mothers to Level III hospitals (providing most a sophisticated level of care) than to transport their critically ill newborns.

State of Perinatal Regionalization in Virginia

by Frederick Wirth, M.D.

The South ranks much higher than the rest of the nation in infant mortality rates, with Virginia ranking worse than approximately 36 other states. The nonwhite infant mortality rate is almost double the rate for whites. While infant mortality rates have declined over the last 40 years, due in large part to perinatal and neonatal technology, serious problems still exist. An additional problem in Virginia is the number of full term but low birthweight (less than 5 lb. 8 oz.) infants born each year.

Many of the current problems in Virginia are related to the lack of a regionalized perinatal care system. Six perinatal centers have been identified, but a complete system of services is not in place. In addition, many low-income patients do not receive the necessary prenatal care, there is a generally inadequate public education about prevention, and there is insufficient funding for perinatal services.

In an attempt to reduce Virginia's infant mortality rate, the Virginia Perinatal Services Advisory Committee was formed in 1980. In 1981, Joint Resolution 218 directed this advisory committee to make recommendations, which it did in a 1983 report to the governor and general assembly. Primary goals outlined in this report are to develop a true regional perinatal system in Virginia by 1988, to ensure the availability of prenatal and delivery care for all women, and to develop a strong consumer advocacy group in Virginia.

Family and Social Impact of Regional Perinatal Care

by Bertha J. Wright, A.C.S.W., M.S.W.

Regional centers must care for the psychosocial needs of every family requiring high-risk neonatal services. The quality of an infant's life

depends not only on medical care but equally on family care. We must not underestimate the importance of bonding for the newborn. Any threat to the pregnancy or to the newborn is likely to affect the ability to bond and thus has implications for the family's capacity to promote healthy growth and optimal development.

Some problems with perinatal regionalization include:

1. Geographical distances for family--mother and/or infant may be hospitalzed and far from family members and friends.

2. Increased costs for family--in addition to expensive medical care, there may be travel, phone, lodging costs.

3. Increased stress on mother and family--natural worries created by a high-risk pregnancy or a newborn in need of special care can be compounded by hospitalization in an unfamiliar, complex institution.

Hospital staff can do much to alleviate the problems created by regionalization of perinatal services. Such efforts are crucial if we are to develop an effective system of services--one that is sensitive to the effects of technology on human beings. With training, the staff can help the family achieve a sense of normalcy, can advocate for the family, and can provide comprehensive discharge planning and follow-up services for the family when it returns to the community.

Funding for staff and other resources are necessary at the community as well as regional level if the system is to operate smoothly. When it comes to pregnant women and infants, we can pay now or pay later. We can pay now, and adequately, in the pregnancy and infancy periods, or we, as a society, can pay later and longer for some children and adults whose special needs reflect previous societal neglect.

A Medical/Neurological Perspective

by Philip I. Markowitz, M.D.

It is difficult to identify risk factors from retrospective studies, although it is possible to identify common characteristics. While risk factors appear to be interactive, a child can be said to be high risk if sufficient and/or a combination of variables are present so that an abnormal outcome can be predicted. Two primary uses of risk factor analysis are risk registries, which accurately identify children but inevitably miss large numbers of those who are impaired, and screening, which can separate those potentially or in fact impaired from those who are not.

It is important to recognize the interaction between biomedical events and social risk factors. There is need for multiple variable assessment tools that incorporate both biomedical and social factors. Such tools can be used for universal screening for abormalities in children as a regular part of their care. This approach may yield better results than merely offering intensive follow-up to those children identified as high risk at birth.

A Psychological/Educational/Social Perspective

by James Gallagher, Ph.D.

Intervention efforts begin with three basic questions:

1. Who is at risk for mild mental retardation?

2. What can be done about it?

3. Who has the responsibility to carry out the intervention?

Development of indicators of risk is difficult; basically indicators are used to find children with handicaps and look for distinctive characteristics. The task of developing accurate indicators is complicated by the difficulty in evaluating low-incidence problems and by changes that occur over time. Gallagher's project in North Carolina used the following factors to identify children at risk:

1. Mother's educational level

2. Father's educational level

3. Whether father is absent

4. Family income

5. Father's work record

6. IQ of parents

7. Sibling, school performance/problems

8. Need for assistance

The intervention project attempted to maximize adaptive behavior-adjustment and competence. The North Carolina project showed a difference of about 10 points in the average I.Q. scores between the experimental group (which received preschool intervention) and the control group (no structured preschool intervention), as well as differences in adaptive behavior skills between the two groups.

Across-the-board screening is not recommended unless intervention is available for all identified. The intervention should not lose out as a result of resources being focused on identification. It is also important to recognize that parents cannot be relied on to do intervention by themselves. Instead "technical teams" can be trained to work with and advise preschool educators, daycare workers, and parents.

Workshop: Social, Racial and Political Issues In Classification and Prevention

A Configural View of Prevention/ Promotion

by Martin Bloom, Ph.D.

There is an acknowledged correlation between the incidence of mental retardation and lower social class status. Any efforts at prevention must address both medical and sociocultural areas and must take into account that much of modern medical technology remains, in effect, inaccessible to portions of our population.

A configural view suggests looking at the individual, his/her biomedical circumstances, and sociocultural circumstances, if prevention efforts are to be effective. The configural view recognizes that a problem, such as the incidence of mental retardation, has multiple causes and therefore multiple channels for solution.

Sociocultural factors may create obstacles to acceptance of prevention actions and may help explain why individuals often do not voluntarily undertake primary prevention. Lack of communication by professionals regarding their motivation for undertaking prevention may cause resistance or passivity on the part of the public. As an extreme example, a 1973 study indcated that some blacks in North Carolina perceived that public health efforts to promote birth control were motivated by a desire for genocide. Professionals must remain sensitive to the beliefs and needs of segments of the general population.

Professionals can help resolve prevention problems by being aware of the cultural pluralism in our society. They can use the norms of a given cultural group, rather than the norms of society at large, to evaluate functioning, although the impact on the society as a whole must be considered. Virginia needs trained advocates who are culturally sensitive and who can recognize the value of manifestations of ethnic competence, even when it conflicts with the expectations of the larger society.

Sociocultural Factors in the Prevention of Functional Mental Retardation

by Jane Mercer, Ph.D.

A recognition that minorities were often labeled educably mentally retarded (EMR) because of misdiagnosis based on cultural differences led to an interest in assessment and testing procedures. Making testing more culturally fair is prevention because it eliminates those counted through misdiagnosis.

An accurate assessment should have two dimensions which, when taken together, identify estimated learning potential. Children's adaptive behavior should be assessed not just in school, but at home and in the community. Standardized tests, such as IQ, should be used as school functioning achievement tests and not as a measure of intelligence. A correction factor to accommodate for sociocultural factors should be applied to the results of standardized tests to produce a more accurate picture of the child's potential.

After assessment, educational intervention should be available for those children identified as having learning problems, but who are not mentally retarded. Suggested procedural steps include:

1. Learning problem is observed by teacher/parent
2. Referral to school level team (special education resources) to suggest educational strategies--no IQ testing, no labeling
3. Review of classroom intervention--at least three distinct kinds should be tried
4. Only now, complete evaluation, including parental interviews, psychological work-up, standardized testing, etc.

Professionals who evaluate children must recognize that many problems result from a failure to structure the child's learning appropriately rather than from the child's lack of ability.

Workshop: The Concept of Prevention as Applied to Epilepsy

by F. E. Dreifuss, M.B., F.R.C.P.

Epilepsy refers to persistent, recurrent seizures that are a result of abnormal electrical discharge in the brain. A single seizure cannot be labeled as epilepsy. When the brain is abnormally affected, it responds with the abnormal electrical discharge that is called a seizure. Among the possible causes of seizures are head trauma, chemical imbalances, genetic predispositions, infections, and environmental poisons such as lead.

Prevention of head injury through use of helmets, seat belts, safety head gear in sports, and enforcement of speed limits is one strategy for preventing epilepsy. Other strategies include vaccination of young children against infections, prevention of adolescent pregnancy, and careful monitoring of high-risk mothers and infants. Because the brain learns a circuit for seizures (kindling), prevention of seizures may help avoid subsequent seizures and therefore epilepsy.

Epilepsy can have consequences far beyond its medical implications. Because seizures are not well-understood by the public, there is a general fear of those who have them and some stigma attached. Estimates of lost income and other economic costs of epilepsy run as high as $4 billion a year. Children who have epilepsy can be deprived of normal education and may also have other conditions such as cerebral palsy or learning disablilties. People with epilepsy may find their vocational activities limited. Even the drugs used to control seizures may cause unpleasant side effects. Five percent of the population has at one time or another had epilepsy.

Early detection and treatment are crucial for controlling epilepsy. Virginia has a comprehensive epilepsy program in place to help the most severely involved patients. Facilities, such as the inpatient unit run by University of Virginia Medical Center, use a multidisciplinary team approach to help patients become more independent. Other important actions for controlling epilepsy are to give EEGs to children whose

parents have epilepsy, to closely follow high-risk children such as the graduates of neonatal intensive care units, and to survey all children age 5 with a questionnaire that can identify cases for further screening.

Fragile X Syndrome

by Judith A. Brown, Ph.D.

Exciting technological advances, such as the ability to look at prometaphase chromosomes, allow geneticists to see small abnormalities that would not be noticed otherwise. To date most new procedures are not feasibly used on a wide scale.

Fragile x syndrome, first described in 1969, refers to a group of male characteristics including I.Q. from 30 to 65, normal birthweight but growth large for age, prominent facial structures, and large testes. The condition occurs once in every 2,000 males and once in every 1,000 females (as carriers only). The marker for fragile x syndrome is found in only 50 percent of the chromosomal spreads of affected males. Males with fragile x syndrome will show no developmental delay at the outset, but 50 percent will become profoundly retarded and 32 percent will become severely retarded. It is easier to detect the existence of fragile x in carrier females than in males.

Prevention and Diagnosis of Fetal Neural Tube Defects

by Fay O. Redwine, M.D., FACOG

One of the problems with screening for elevated alpha-fetal protein (AFP) levels to identify neural tube defects in infants is that most of the cases re not born to high-risk women. Mass screening of maternal serum is the only ccurate way to catch the majority of fetal neural tube defects, but there are many controversies associated with this approach.

The current screening test has a 90 percent false positive rate. Serum AFP levels can be elevated if the woman is carrying twins, if the

incorrect gestational age is used, or for a variety of nonspecific reasons.

There is concern that false positive tests might lead to the abortion of normal fetuses. There is also currently a dearth of facilities to handle widespread maternal serum screening. The cost of mass screening is another factor to weigh. To screen 1,000 pregnant women would cost about $33,225. About 50 of those tested would have elevated AFP levels and further tests would be required to identify the one or two with actual open neural tube defects.

Mass screening remains, however, the only way to identify 90 percent of the cases of open neural tube defects in utero. The technology exists to reduce the high rate of false positive tests, so that will become less of a problem as time goes by. Finally, the cost of screening, while high, is not that far out of line now and might be expected to drop.

Vitamin Responsive Disorders

by Barry Wolf, M.D., Ph.D.

From a biochemical perspective, vitamins can be described as molecules that interact with enzymes to ensure normal nutrition and metabolism. In 1966, federal law declared vitamins a drug so that a prescription was necessary for any dosage 150 times the minimum daily requirement. (Minimum daily requirements were established through animal research.) The Freedom of Nutrition Bill of 1976 reversed the 1966 legislation and labeled vitamins nutrients rather than drugs. It has only been since 1976 that megadose therapy has emerged. There is a lot of controversy involved with it, and all the information is not in on the advantageousness of such an approach.

We must distinguish between vitamin deficiencies and vitamin dependencies. Generally, vitamin deficiencies are the result of dietary problems, are acquired, and take time to develop. Vitamin dependencies are more likely to be inherited, develop rather quickly, and may not be a result of a vitamin deficiency at all. Vitamin deficiency disorders can be treated by returning a normal amount of the missing vitamin to the system. A vitamin dependency disorder, or inborn error of metabolism, may require megadose therapy.

There are around 30 conditions in man that can be treated by megadose therapy with various degrees of improvement. Homocystinuria, for which

all newborns in Virginia will be screened beginning in 1984, is one such disorder. Half of the individuals with homocystinuria will respond very well to large quantities of vitamin B_6. The rest of those with the disorder have to be treated less drastically and less successfully with diet manipulations.

We are learning more all the time about the identification and treatment of vitamin responsive disorders. A pilot project in Virginia will use the same blood sample used to screen for PKU to test for biotinadase deficiency. This very rare disorder results in severe consequences including mental retardation. Because the disorder responds very well to therapy, it is an ideal research project. The study project will help identify incidence of the disorder and permit additional work on the effectiveness of vitamin therapy.

A Model Pre-Term Birth Prevention Program

by Paul Meis, M.D.

The North Carolina Experience

by Mary Lou Moore, R.N.C., M.A., F.A.A.N.

North Carolina has begun a prevention program to lower its 8 percent preterm birth rate. Interest in such an effort has developed over the last 10 to 12 years as it has become clear that current prenatal care services have not affected the preterm birth rate. The program described here uses the Creasy model of identification of at-risk pregnant women followed with education and aggresive treatment.

The North Carolina program uses a team approach to health care providers about participating in the prevention effort which is supported by a federal grant. To establish the regional program, the team:

1. Sent letters to public and private providers of prenatal care (75 percent of births from private practice physicians, so their involvement was crucial).

2. Spoke at staff, association, and society meetings.

3. Met with provider group to discuss goals of project, assessment tools, etc.

4. Contacted individual practices to ascertain desire to participate (non-participants became control group).

5. Monitored individual practices for implementation of model.

The key concepts in the North Carolina prevention project/study are teamwork, leadership in the local community, flexibility to allow individual practices to adapt the program, and provision of all necessary forms and materials.

Preventing Pre-Term Birth

by Preston Lea Wilds, M.D.

In 1981, Virginia ranked 32 in the United States in infant mortality. Preterm births account for 85 percent of all early neonatal deaths. Unfortunately, conventional prenatal care programs have proved largely ineffective in preventing preterm birth. Neonatal care units can help save many infants born in preterm deliveries, but such units are not accessible to all patients due to cost or geographic factors. In 1981, Virginia spent $25 million for neonatal special care hospital expenses.

A prenatal care program developed in California by Dr. Robert Creasy reduced the rate of preterm delivery from 6.75 percent to 2.43 percent. The March of Dimes is funding a four-year study of the Creasy model, which uses existing technology, but emphasizes an innovative educational approach, in five centers. The preliminary results of this study will be available in the summer of 1984.

The components of a preterm labor prevention program include:

1. Scoring patient for risk of preterm labor
2. Patient education in signs of preterm labor
3. Staff education
4. Extra prenatal care visits for women at risk
5. Aggressive use of tocolytic therapy
6. Coordination of inpatient/outpatient care.

State of the Art in Virginia

by M. Jo Bunce, M.Ed.

Services for handicapped children in Virginia are divided into infant development programs for children below age 2 and public school programs for those age 2 and older who are identified as needing special education. Virginia's mandate for public school special education dates to 1968 legislation requiring services for the hearing impaired, ages 2 to 20 years, and 1972 legislation requiring services for all handicapped children ages 2 to 21. The early 1970s was also the period for the emergence of trained child development specialists in Virginia.

Public school programs are funded by the state, federal, and local governments. Infant development programs in Virginia are generally funded by community services boards and gap-filling dollars. Currently 2 to 3 percent of the handicapped population is served by early intervention programs, a rise from 1,000 children served in 1974 to 5,000 children served in 1982. Preschool programs offer services in both home-based (33 percent) and center-based (67 percent, with vigorous parental involvement) settings.

No longitudinal research has been carried out in Virginia to measure the effectiveness of early intervention programs. Solid evidence of their validity would ensure that early intervention programs receive the funding that they require. There are 45 infant programs in Virginia now. Interdisciplinary and interagency cooperation will be necessary to build upon and expand the range of services that currently exist. Additional study is also necessary to determine what services early intervention programs should include in order to make them as appropriate as possible.

Model Intervention Programs with Young Handicapped Children

by Judy Howard, M.D.

Early intervention techniques can prevent mental retardation (IQ less than 80), can correct or suspend further deterioration of sensory impairments, can decrease medical and emotional problems, and can help alleviate family stresses that contribute to divorce, child abuse, and other problems. A number of recent studies demonstrate that attention, stimulation, and education of the at-risk infant and general enrichment of its environment have positive effects.

There is evidence that children who receive infant and preschool services are at lower risk of needing special education later. However, early intervention changes do take time. Generally, it is not possible to diagnose mild or moderate retardation before 6 months of age, so it is essential to screen children in that age group. Intervention programs and curricula must respect and take into account the life style of the population to be served. Because maternal behavior so strongly affects the intellectual development of children, it is crucial to involve mothers in early intervention programs.

The Administration on Developmental Disabilities' Influence on Prevention and Early Intervention

by Jean K. Elder, Ph.D.

The Administration on Developmental Disabilities is one of four program administrations located in the Office of Human Development Services of the Department of Health and Human Services. The President's Committee on Mental Retardation, a committee established by executive order, is also found within the Office of Human Development Services.

Public Law 95-602 established the Administration on Developmental Disabilities. The four aspects of the law include:

1. A DD council in every state responsible for planning for disabled citizens and for identifying priorities.

2. A protection and advocacy agency in every state responsible for protecting the legal and human rights of the developmentally disabled.

3. Funding for competitive research and demonstration projects--all proposals reviewed by outside experts; projects can receive a maximum of $150,000 to use over a 12-to-17-month period.

4. Support for University Affiliated Facilities (UAFs) that train specialized and generic professionals who will work with developmentally disabled individuals. In addition to interdisciplinary training, UAFs provide direct services, disseminate information, and encourage research.

The overall mission of the Administration on Developmental Disabilities is to act as the lead agency on issues related to persons with disabilities.

Although the legislation authorizing the Administration on Developmental Disabilities does not specifically mention prevention, the agency focuses on tertiary prevention through attention to the school to the

life-after-school transition period. The Administration on Developmental Disabilities' goal is to help persons with disabilities achieve maximum self-sufficiency.

The Role of Higher Education in Prevention

by Ruth Diggs, Ed.D.

A philosophical understanding of the role of higher education in prevention of mental retardation outlined in the fifth annual report of the President's Committee on Mental Retardation (1971) is still valid today. That report recommended:

1. Innovative approaches from a variety of disciplines to focus on quality of life rather than on abstract theory.

2. A trend away from departmentalization to multidisciplinary approach to prevention.

3. A focus on the entire life cycle.

4. A focus on the "whole" person in his environment.

5. Development of university curricula on human ecology with a priority of preventing mental retardation.

Recommendations

1. Institutions of higher learning in Virginia should be encouraged to modify their curriculum plans to include relative and important aspects of prevention for all of their students. The curriculum for educating those who work with children and their families should acknowledge that high-risk children include not only the handicapped but also the children from social, cultural, ethnic, and economic backgrounds different from the so-called norm. Training in cultural pluralism should be incorporated into all professional curricula and inservice training programs utilized for administrators and service providers involved in prevention programs and activities.

2. Virginia should continue its efforts to encourge coordination of agency services, in regard to training preservice and inservice personnel from institutions of high learning, to become actively

involved in state and local coalition activities and, whenever appropriate, to become involved in the national effort to combat mental retardation and other developmental disabilities and ameliorate their effects.

3. Virginia should encourage relevant personnel from institutions of higher learning to become actively involved in state and local coalition activities, and whenever appropriate, to become involved in the national effort to combat mental retardation and other developmental disabilities and ameliorate their effects.

Historical Perspective on Federal Involvement

by Laverdia Roach

President John Kennedy created a panel in 1961 to research issues related to mental retardation and present a plan to address those issues. In 1966, President Lyndon Johnson established the President's Committee on Mental Retardation. The committee provides advice and assistance to the president on mental retardation issues through an annual report. The responsibilities of the committee include:

1. Evaluation of the national effort on behalf of retarded persons.

2. Identification of the effectiveness of services.

3. Liaison between the federal government and the states.

4. Development and dissemination of information.

Prevention is the highest priority of the President's Committee. Its 1981 annual report dealt exclusively with that topic. The basic assumptions of the President's Committee are that prevention of mental retardation is a realistic and achievable goal and that federal efforts must be coupled with state and local commitment of personnel and funds.

Hypothyroidism: Screening and Treatment

by Robert Lovinger, M.D.

Hypothyroidism has much higher incidence (one in 4,000 births) than the disorders discussed by Dr. Roth. Screening is essential because hypothyroidism is difficult to diagnose clinically unless a cluster of symptoms is seen. Early diagnosis is of utmost importance. Patients whose treatment starts late will show improved physical growth but impaired IQ. By age 6 months, central nervous system damage will occur if treatment has not begun. Eighty percent of the patients whose treatment began by age 3 months show normal IQ.

Hypothyroidism is seldom predicted--80 percent of cases are due to spontaneous mutations. It is very cost effective to treat the disease. The current program in Virginia is working well, but there is a need for increased cooperation between hospitals and screening labs so that a diagnosis can be made early. There is also a need to use improved testing methods or to repeat screening at age 2 months to catch cases missed in the initial screening. Overall, more funding is needed to increase follow-up and improve services.

Newborn Metabolic Screening: Exploration of a New Frontier of Pediatrics

by Karl Roth, M.D.

Screening for metabolic disorders is a concrete example of prevention. Laboratory tests are available to identify disorders having such nonspecific clinical signs that they cannot be identified otherwise. It is important to balance the costs and benefits of a screening program with

the costs and benefits of treatment. A variety of treatments may be effective for metabolic diseases. The mainstay of treatments today are diet manipulation, vitamin therapy, and drugs. Research in organ transplantation, enzyme replacement, and genetic engineering continues.

Phenylketonuria (PKU) testing is well-established in Virginia. A blood sample taken on day 3 of life will yield reliable results. Although diet manipulation can control PKU, the disease may have lasting psychological effects. Frequently PKU patients have learning problems that are a result of their disease and not the result of emotional problems. Females treated for PKU are at risk of bearing damaged children. Better results are obtained in preventing these second generation problems if treatment is begun before rather than during pregnancy. A national registry of PKU patients would make follow-up for females more feasible.

Virginia will begin screening for maple syrup urine disease (MSUD), homocystenuria, and galactosemia in 1984. While these disorders are rare (e.g., MSUD occurs once in every 225,000 births), the cost of mass screening and treatment of a single case can be less per year than the cost of care if that case is not identified. There are other serious disorders, such as organic acidemias, that are not currently appropriate for mass screening. It would be wise to at least run a chromatography of the urine of infants in neonatal units in an attempt to identify these disorders. Continued research on these and other diseases is necessary to develop accurate screening techniques.

Strategies for Prevention of Severe Head Injuries

by Lorne K. Garrettson, M.D.

While severe head injury is relatively uncommon, it accounts for the majority of mental retardation disability that is the result of head injury. A head injury is a bump or blow to the head accompanied by (in order of increasing severity) changed mental state but full recovery, lacerated scalp or fractured skull, permanent mild disability, permanent severe disability, or death. The overwhelming cause of head injury in the postnatal period is automobile accidents. The second most common cause of severe head injury is falls. Studies show that younger children, particularly those under 1 year of age, are most susceptible to head injury.

It is difficult to gather statistical data that directly links head injury and mental retardation. One fairly accurate estimating technique is to assume that the number of severe head injuries is comparable to the number of deaths each year from a particular cause. As an example, one could assume that in a recent year at least 31 children in Virginia, 4 years old and under, had severe head injury causing permanent disability from automobile accidents because there were 31 deaths from automobile accidents in that age group. The rough numbers generated in this way give further evidence of the need to prevent or reduce the severity of head injury in young children.

A number of effective prevention strategies exist. Enforcement of the Virginia child restraint law and widespread use of child safety seats would eliminate many cases of head trauma. Window guards, inexpensive and simple to install, can be added to any window to prevent the possibility of a fall. Children's play areas can be made safer. Research indicates that a blow to the head with a *g* force greater than 50 is likely to cause severe head injury or death. A fall head first on concrete from a height of only one foot causes a *g* force of 500. Removal of concrete play areas and substitution of sand or wood chips instead would remove the potential for severe head injury that occurs when children fall in playgrounds.

Lead Poisoning: A Legislatively Preventable Cause of Mental Disabilities

by Jean E. Shelton, M.D.

Lead poisoning has political, economic, and health aspects. Nationally, about 4 percent of children 6 months to 5 years of age have high blood lead levels. The rate is even higher among black inner city children--18.7 percent have lead levels above acceptable levels. The evidence that high levels of lead in the blood cause miscarriage, blindness, seizures, mental disability, and even death, is readily available. Children are exposed to lead when they eat chips of lead-based paint, breath air polluted by lead exhaust, and inhale lead particles in dust or dirt. Even slightly elevated lead levels may affect visual and fine motor coordination and lower IQ scores.

Screening is necessary to attack the lead poisoning problem. All children should be tested for blood level at age 2--high-risk children should be tested more often. It is equally as important to remove the source of the poisoning. Localities should develop ordinances to require inspection for lead paint and correction of any problems before property is rented. Federal action will be necessary to reduce automobile and industrial lead pollution. Overall the public needs to be educated about the widespread lead poisoning problem.

Reducing Hazards from Poisoning and Drowning

by Daniel A. Spyker, M.D., Ph.D.

Emergency room visits by children are caused by (in order of numbers) falls, bike accidents, poisoning, burns, and drownings. One in 10 children age 1-2 years has a poisoning accident each year. Strategies to prevent poisoning have had mixed results. There is some evidence that young children are attracted by the "Mr. Yuck" labels that are supposed to warn them to stay away from dangerous substances. Efforts to educate adults and children about the dangers of accidental poisoning have had limited success, but child-proof or child-resistent containers have had a significant impact. There is also evidence that people do call poison control centers.

Drowning is rarer than poisoning, but frequently has more serious consequences. Drowning is the third overall cause of accidental deaths. Swimming pools present the greatest hazard to children. While more injuries occur in private than public swimming pools, there is a need to adequately fence both types. Teaching toddlers to swim is another effective means of reducing accidental drownings or near drowning.

Pregnancy in Teenagers: Consequences and Their Prevention

by Richard R. Brookman, M.D.

1. One of every 10 American girls will experience at least one pregnancy before her 18th birthday; one in every four, before age 20.

2. Half of all premarital pregnancies in teenagers occur within six months of the first sexual intercourse; one-fifth occur within the first month; contraception is least likely to be considered or discussed with a partner at this time in a relationship.

3. The total number of births and the birth rate have declined for every age from 14 to 19 years since the mid-1970s. However, the total number and rate of out-of-wedlock births have increased. The birth rate for white teenagers has increased. The total number of abortions for teenagers has increaed (as it has for older women). Overall, the total number of pregnancies and the pregnancy rate has changed very little.

4. Reasons for nonuse of contraception:

   a. Adolescent omnipotence - belief that "it can't happen to me"

   b. Incorrect beliefs about risk of conception, fertile time of month

   c. Intercourse not anticipated

   d. Fear of side effects

   e. Partner objection

   f. Parent objection

   g. Lack of access (barriers to health care)

5. Medical complications of early pregnancy:

   Maternal--increased risk for:

   a. Bleeding in first and/or third trimester

   b. Anemia - often borderline iron stores, other nutrients at onset of pregnancy

   c. Prolonged labor

   d. Need for C-section (greater need due to size discrepancies only in younger teens)

   e. Toxemia (hypertension)

   f. Sexually transmitted infections--in high-risk group, may have other partners

   g. Cervical cancer at young age--due to exposure of immature cervix to carcinogenic agents (trauma, secretions, infections)

   Infant--increased risk for:

   a. Premature birth

   b. Low birthweight (may be due to younger teenagers having earlier menarche and smaller body size when fertile)

   c. Neonatal mortality

   d. Neurological deficits

   e. Exposure to sexually transmitted infections--gonorrhea, chlamydia, herpes, syphillis, group B streptococcus

6. Psychosocial correlates of early pregnancy:

   a. Interrupted/incomplete adolescent development

   b. Interrupted/incomplete education

   c. Limited career options and earning power

   d. Premature marriage--frequent instability, divorce

   e. Larger family size at younger age

   f. Depression--suicide risk

g. Stigma of illegitimacy for child, mother

h. Childraising problems--increased risk for child abuse

i. Risk of repeating early pregnancy in successive generations

NOTE: It may well be that early pregnancy is a symptom or concomitant, not a cause, of these correlates and that they, as well as early pregnancy, result from psychosocial and cultural-economic disorders during early childhood. The adolescent may be "destined" for these outcomes whether or not pregnancy occurs, without appropriate intervention. Pregnancy, occurring almost as an "accident" in this context or as an intended attempt to resolve problems, serves only to complicate the situation. The degree of support available from family, partner, community, and agencies may determine which, is any, of these consequences will occur.

Preventing Adolescent Pregnancy in Virginia: A Call for Action

by Martha M. Conley, Ph.D.

Recommendations:

Avoid policies that foster male irresponsibility in dating and parenthood. Encourage job skills training program for both men and women. Secure stable funding for the care of pregnant teenagers, as well as for programs to prevent adolescent pregnancy. Set up a series of statewide hearings on a regional basis where professionals from education, health, social services, juvenile justice, and mental health and mental retardation can meet to discuss the consequences of "children having children" and coordinate their response.

The problems raised by teen pregnancy are many. Besides the medical and psychological consequences cited above, there are dire economic and social consequences for these young women and their families. Over 50 percent of welfare costs are to adolescent mothers. Teen mothers are, on an average, two years below grade level. The cycle of early childbearing repeats itself generation after generation.

Sex education and contraceptive instruction alone will not decrease the rate of adolescent pregnancy because sexual activity and the subsequent birth of a child fulfill other basic psychological needs. Between

1970 and 1979, there was a 66 percent increase in adolescent sexual activity. We must teach adolescents to make intelligent choices and to recognize the responsibilities inherent in sexual activity.

A Model Prevention Education Program for Adolescents

by Sarah Litch

Junior and senior high school students in Indiana have been educated systematically in the causes of mental retardation and preventive strategies since the introduction of a curriculum focusing on prevention in 1978. The program was developed from a survey on what health education teachers were currently teaching in mental retardation and their willingness to teach a specialized curriculum. An interdisciplinary advisory board was formed to train teachers and oversee implementation of the curriculum. A similar college-level course is now taught to special education students.

The curriculum represents a balance of biomedical and behavioral prevention strategies. Emphasis is also placed on environmental influences in the incidence of mild mental retardation. Male students are instructed in their own responsibiliy regarding prevention of pregnancy, no less that that of their female partners.

Further longitudinal studies are needed to assess the curriculum's effect on student behavior later in life. Pre-and post-tests on 2,000 participating students indicated an increase in cognitive knowledge, ranging from 19 to 69 percent.

Litch's curriculum can be used in tandem with a family life curriculum. No matter what rubric is used with these materials, they are difficult to sell to local administrators. Prevention professionals must learn the politics and strategies needed to get into the school system. Each school has its own peculiar climate. To convince a school system to use a curriculum, no matter how well-documented its effectiveness, one must spend some time learning local points of view.

Genetic Counseling

by Robert C. Baumiller, Ph.D.

Genetic counseling is an educational process used to inform individuals about their risks for bearing a child with a genetic disorder. Genetic counseling is sought by individuals affected personally by genetic disease, by couples who have a child with a problem or by couples or individuals who believe they may be at risk for bearing a child with genetic disease. The genetic counselor's task is to relay information on risks and methods of avoiding risk, as well as striving to ensure understanding of that information. Once this information has been conveyed, the genetic counselor's job is finished. The moral and ethical decisions that follow must be made freely and solely by the affected individuals and their families.

The general belief is that genetic counseling helps people make informed choices regarding the genetic risks in childbearing and, ultimately, leads to prevention of some instances of genetic disease. If a genetics center becomes very good at prevention, it is probably exceptionally good at persuasion. Its patients are probably making decisions that genetic counselors, largely middle-class individuals, would make or would consider appropriate. As genetic counselors, we are aware of the great variety of choices made in counseling situations and the fact that they are shaped by personal history, values, and socioeconomic background. The same outcome is perceived in a variety of ways by the individuals whose lives are affected. We must preserve that individual freedom of choice, even with imperfect methods of prevention and treatment.

First, we must make sure couples realize the kind of decision they are facing and that their choice will be mutual. They must be asked to consider all the possible outcomes of different choices. With the assistance of the March of Dimes, Georgetown University is developing a program to increase clergy's awareness of what actually happens in a genetics clinic, what occurs during a counseling session, and the manner in which alternatives are presented to the patients. We hope this will result in an informed support group for those persons faced with genetic

decision-making. As a back-up to traditional genetics counselors, these trained clergy can help individuals make decisions such as whether to marry, whether to have children if they marry, and what alternative methods of parenting might be suitable. We want to ensure that individuals receive all the support they need in looking at all aspects of their lives which will be affected by the choices they make.

Issues in Genetic Technology

by Thaddeus E. Kelly, M.D., Ph.D.

I would like to be relatively specific in addressing the ethical concerns that arise out of the application of prenatal diagnosis, which I think will be the topic of much larger public debate than in the past. Recent advances in genetic technology leave us with a new set of dilemmas. Two examples of new methods in prenatal diagnosis include the use of recombinant DNA to determine changes in genes and the refinement of the chorionic biopsy, a procedure used to diagnose certain genetic disorders by aspiration of fetal tissue as early as eight to 10 weeks in pregnancy. Thus, prenatal diagnosis can be safely made within the first trimester of pregnancy, a time when many women will consider termination acceptable if faced with the birth of an affected child. With the creation of such capability, we must examine carefully a number of issues related to their utilization. Prenatal diagnois is practical from a cost-effective perspective, but we must maintain respect for individuality and the rights of each person regarding reproduction. Questions we will need to address include: How will these new diagnostic techniques be used? For whom will they be used? Who will pay for their use?

Our educational system must adequately ensure that all individuals at risk make informed decisions. We must guarantee that our society is one in which these issues can be discussed. We must also ensure access to genetic services through the development of facilities throughout the state and make certain that there are funds available to protect these services when the individual lacks adequate financial resources.

Some Thoughts on the Baby Doe Issue: A Neonatologist's Perspective

by Frederick Wirth, M.D.

Recent years have seen a dramatic drop in infant mortality. Many infants surviving today through medical intervention are left to live with severe impairments and medical conditions.

The Baby Doe regulations are *intended* to protect handicapped infants from discrimination by preventing the denial of medical care. However, the legislation is too vague. Lacking definition, it fosters the denial of the family's rights to privacy and autonomy. It prevents the child from exercising the right to die. The family has a right to be protected from intrustion by the press and by the government.

Decisions should be made by those who have to live with them. The government is responsible for educating the public concerning the laws. The medical community has the obligation to provide correct health care and information. Ethic review boards are a mechanism used by many institutions to review specific cases. The institutions clearly state their policies regarding newborn care, allowing the consumer to choose services with full knowledge of what that choice entails.

Prevention: From Need to Reality

by Dorothy I. MacConkey, Ph.D.

Public Law 94-142 has not accomplished all that we hoped it would. There is still a gap between services that are available to support the disabled and their families and their awareness of such services. Many excellent support services exist, but too few families know and take advantage of them.

It is easy to just think of prevention in terms of prenatal care and early intervention. "Drop in" deliveries are still one of the most

frequent, preventable influences on the incidence of mental retardation. However, we must think of prevention in the global and lifelong sense. We must be wary of the power and effect of labels, such as "mentally retarded," and prevent careless or unnecessary use of labels.

We must also think in terms of the social definition of prevention. Do we do all we can to prevent the social isolation that is characteristic of the lives of so many deinstitutionalized persons? The developmentally disabled are frequently denied the common social aspects of adult life, such as marriage, dating, or working full time. I sense that there has been a "retarding" of our efforts on behalf of the disabled in the last 10 years. We have become complacent because of the large number of professionals working in the field. There is an unfortunate tendency on the volunteer side to think we do not need to work as hard. We must prevent any kind of diminishing of our efforts on behalf of the developmentally disabled.

We must also broaden our definition of prevention in terms of what we do in the public policy sector. If you look at the public policy response to human needs, crisis situations always elicit more immediate support than ongoing, ever-present types of problems. So we must work twice as hard to affect social policy.

We must also be cautious about forming advocacy coalitions which attempt to unite too many diverse groups under one rubric. Spontaneity and quality can be lost when an organization becomes too large and too structured. We must remind our social groups that 50 percent of mental retardation still affects the victims of disadvantaged environments and an unequitable social system. We must charge our coalitions to prevent this inequity from continuing to occur. We must find creative and coordinated uses of money at the local level. We must invent new ways of making the same, and even decreasing, amounts of money go farther.

What If . . . A Parent's Perspective on Prevention

by Susan B. Spielberg

We must remember that we are talking about individual lives when we discuss prevention. I love my son Jonathan for what he is, but I also mourn for what he is not. What ethics are we dealing with? I am concerned with the ethics of here and now.

I was pleased with the outcome of the Baby Jane Doe case. I am relieved that one child will not have to spend 20 years in a purgatory on earth. The parents will go on.

My perspective is shaped by my experience with my son, who is 15 and requires supervised care 24 hours a day. I deal with the ethics and ethical judgments of educators, agencies, and social services every day. Prevention efforts treat the symptoms, not the cause, of the real problems experienced by handicapped individuals and their families--the sorrow, the frustration, the burnout of trying to cope with priorities set by others. Who is playing God here?

Terminology and Public Attitudes

by John A. Chappell, Jr.

As a representative of those disabled persons who are alive, I am concerned that we not lose sight of the fact that discussions of prevention concern real people. We do not have a crystal ball that allows us at birth to predict a child's potential for a fulfilling life. I work daily with people whose lives have been hell on earth because of public attitudes, not because they are incapable or lacking in self-direction. Rather, people's values have been placed on their lives. Others have made the assumption that they are incapable of doing anything. Often the attitudes of others about what persons with disabilities can achieve are more limiting than the disabilities themselves.

When discussing prevention, we must be careful that our desire to prevent disabling conditions is not mistaken for disparagement of those persons with disabilities. The nondisabled must understand that people with severe disabilities can lead fulfilling lives. Doctors need to learn this as do many family members. Despite the best of intentions, many families are patronizing and overprotective of persons with disabilities.

Society's attitudes are reflected in the language used in reference to persons with disabilities. Words, such as "malformation" or "deformed," which are bandied about in discussions of prevention, perpetuate negative images of the disabled.

While agreeing that we share a responsibility to assist in prevention, not for cost-effectiveness reasons, but on behalf of human potential, I submit that we must simultaneously guard against erosion of the civil rights of persons with disabilities. The disabled must have

equal access to the community. Society must not *prevent* them from leading fulfilling lives.

Workshop: Prevention of Alcohol Related Birth Defects

by Robert J. Sokol, M.D.

Fetal Alcohol Syndrome (FAS) is not the third leading cause of mental retardation. It is the third *known* cause. We must be careful about what we say regarding FAS. About 400 FAS victims have been recorded in world literature. There is no strong evidence that one drink a day during pregnancy causes Fetal Alcohol Syndrome.

Seven years ago, one survey showed that 90 percent of women knew drinking alcohol during pregnancy might pose a problem. Nine to 10 percent of the population are alcoholic--this is where we need to focus our efforts. FAS is a problem, and it is preventable.

It is very difficult to identify Fetal Alcohol Syndrome before age 1. The most common symptoms of FAS are growth retardation, abnormal facial features, e.g., flat nose, thin upper lip, cleft palate, and central nervous system problems. Prenatal alcohol exposure may account for 5 percent of all congenital anomalies.

Prevention efforts in FAS must target the appropriate part of the population. Reasons for underidentification of alcohol-abusing obstetrical patients include: vague criteria, lack of training among physicians and other health professionals, perceived inability to help, concern regarding offending the patient, and denial by the alcohol abuser to self and others. The answer to FAS is professional education for individuals who see women during pregnancy.

Scare tactics are not effective. Screening for alcohol abuse should be an integral part of the patient's history. A nonjudgmental and concerned attitude is crucial to gaining patient trust and cooperation.

To obtain an accurate assessment, it is often helpful to suggest a range of expected responses to the patient. By suggesting relatively high amounts of alcohol, the physician or nurse implies that this is a routine disclosure. Further questions are used to probe the circumstances and pattern of drinking.

If the health professional suspects alcohol abuse, a number of steps can be taken:

1. Tell the patient that limited drinking will help her to have a healthier baby.

2. Refer the patient to a specific alcohol program, if necessary.

3. Maintain contact with the patient.

4. Document the diagnosis and referral.

Proper Parenting for Child Abuse Prevention

by Gerald W. DeWitt, M.D.

Children today are one of our most endangered species. The phenomenon of child abuse has developed from a number of influences in our society. We have only recently begun to question the presumption that all parents care for their children and will act in their best interests. Historically, parents have had a custodial right akin to a property right over their children. In the last 20 years, social attitudes have changed slowly in the direction of recognizing deliberate physical and sexual abuse of children. "Child abuse" is a general term which refers to emotional, sexual, or physical abuse, neglect, and/or abandonment. Secondary prevention, or the reporting of abuse, is occurring. We need more primary prevention efforts.

In 90 percent of reported cases of child abuse, the problem is parental inability to protect and nuture the child, not an intent to harm or destroy the child. Regretably, 10 percent of child abusers--those with a diagnosable psychiatric disorder who are capable of inexplicable atrocities regarding their children--receive public attention. Most child abusers are real people with real problems, not monsters. They represent all socioeconomic levels and educational backgrounds. As a group, they frequently share a history of being abused themselves, i.e., poor parenting models, limited understanding of child development, and little knowledge of childhood demands. In one study of identified child abusers, 90 percent of the respondents indicated that they did not know how to discipline their children, how to nuture or care for them, or what to expect as a parent.

The cycle of abuse begins with this lack of knowledge. The parent spanks the young child when he cries, whatever the reason. The child learns he cannot trust people, that no one loves him, and that he is worthless. This socially isolated, emotionally withdrawn child grows into an adult with no conception of appropriate displays of affection or emotion. Potential child abusers can be identified by the way they feel about themselves and other people and often by the manner in which they relate to peers, co-workers, and other adults. They must be taught how to relate to others.

Remedial parenting education and daycare facilities located in high school settings are two program models which have been shown to succeed in preventing child abuse. In the latter, students work as volunteers in the daycare setting so they can experience both the problems and pleasures of parenthood. They learn how to handle the inevitable conflicts of raising children; they may decide parenthood is not what they want based on realistic experiences.

We need Family Life Education in the schools for grades K through 12. Other programs which can be used to address the problem of child abuse include efforts to identify high-risk/high-stress families and self-help groups, e.g., Parents Anonymous, family therapy, and foster care. Further recommendations would include increased mandatory reporting of child abuse and neglect. Lawyers and clergy are two groups with high potential for witnessing abuse that are currently not required to report child abuse and neglect. Neighbors and relatives of abused children report abuse more than anyone else. Obviously, we can and must do more to prevent it from occurring in the first place.

Community Advocacy for Children At-Risk

by Joan H. Kammire, M.S.W.

Families often present multiple problems to human service agencies. It can be frustrating and overwhelming for the professional attempting to deal with numerous crises or problems simultaneously.

Families at risk for child abuse can be identified by observing the vulnerabilities of parents, familial stress, and parental coping abilities. Many abusing parents have been the victims of poor parenting themselves and are caught in a cycle of behavior known as the "world of abnormal child rearing (W.A.R.)," characterized by low self-esteem, role reversal, isolation, and unrealistic expectations.

When dealing with abusing parents, it can be helpful to deal with their vulnerabilites one at a time. Intervention with abusing parents begins with assisting them in reducing their stress, finding resources for their basic needs, e.g., food, shelter, socialization, and helping them practice new ways of coping. Solutions must involve medical, legal, social, and psychiatric insight. Secondary interventions focus on inter-agency cooperation in sharing knowledge, techniques, and resources for dealing with stressed, abusive parents with numerous problems. Thirdly,

multidisciplinary teams must work to address community issues such as resource development, public education, and professional education.

Rather than removing a child from his family, it may be wise to help the family deal with concrete problems such as discussing payment arrangements with a landlord. This helps to build a trust relationship which is essential if families are to make use of available services. Being able to meet their basic security needs can help get a family back on track.

Shaping Local Initiatives Through National Networking

by Elizabeth Boggs, Ph.D.

Successful coalitions usually share certain qualities and conditions and are based on a set of common interests that attract members. Coalitions require compatability of members and good internal and external communications. The coalition must develop a consensus of its purpose that leads to action. Ideally the results of the action will reinforce the members of the coalition and lead to a renewal of action.

Coalitions must make hard choices about what to target for action. A list of criteria suggested by Dr. Robert Guthrie that a prevention coalition might use in selecting targets includes:

1. Causes and means of prevention well understood;
2. Significant number of cases produced;
3. Cost of prevention is reasonable;
4. Cooperation of public and professionals is likely;
5. A gap in services exists;
6. A model program exists;
7. Measurable results are possible;
8. The effort is timely.

Based on these criteria, a number of subjects are possible targets for current coalition action, e.g., lead poisoning control, Rh Hemolytic disease, child auto restraints.

The Prevention Council: A Model Interagency Coalition

by Madeleine Chandler, R.N., M.S.N.

The Prevention Council is a volunteer coalition of agencies located in Planning District Ten that attempts to reduce the incidence of birth defects through public information efforts. The group had its origins in a 1976 effort by a number of community groups, including the local Association of Retarded Citizens, Region Ten Community Services Board, March of Dimes, and University of Virginia Hospital, to study local prevention possibilities. Based on the results of this study and the interests and talents of members, the group decided to focus initially on prevention of adolescent pregnancy. The first public awareness campaign to address this issue, held in March 1977, encouraged utilization of existing services. The range of services available was highlighted in posters, newspapers, television, radio spots, and flyers at fast food restaurants using the theme "Having Babies Isn't Kid Stuff." The success of the first campaign convinced the coalition to formalize and continue its efforts.

Over the years the Prevention Council has evolved into a small, but active group that presents an annual campaign. Plans for campaigns, information sharing, and inservice training take place at monthly meetings. The interest of the group has expanded beyond adolescent pregnancy; and issues such as wellness before, during, and after pregnancy, unplanned pregnancy, and prevention of injuries by use of child auto restraints, have been the topic of annual public education campaigns.

Whenever possible the council makes use of existing materials (e.g., brochures from March of Dimes, Lung Association, Association for Retarded Citizens) and emphasizes services that are currently available. The philosophy of the Prevention Council--that a volunteer organization can help reduce the incidence of developmental disabilities and do so without huge cost and time commitments--has not changed since its inception and remains viable today.

ACTION AGENDA FOR THE PREVENTION OF MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES

The material in this section has been developed by prevention advocates and experts from across Virginia and the nation. Numerous contributors helped identify categories and made the specific recommendations in each category. The Action Agenda is sanctioned by no one agency, organization, or department, but rather belongs to the participants at the 1983 Virginia Mental Retardation/Developmental Disabilities Prevention Conference.

During the conference, participants discussed and refined the recommendations included here. There were opportunities at workshop sessions and at two evening meetings to revise this document. The Action Agenda that emerged from the conference reflects the latest in scientific knowledge about prevention of developmental disabilities blended with the practical experience of workers in the field.

The Action Agenda is intended to be more than a wishful catalog of actions that could be taken in Virginia. It is a well-considered list of actions that can and should be undertaken to reduce the incidence of developmental disabilities. A statewide coalition is now being formed to set priorities and to work for implementation of selected recommendations. This compilation of recommendations will count for very little if it is not put to use. Help to make the Action Agenda a powerful guide for increasing prevention activities in Virginia.

AN ACTION AGENDA FOR PREVENTION OF MENTAL RETARDATION DEVELOPMENTAL DISABILITIES IN VIRGINIA

Genetics

1. Genetic Screening and Counseling
2. Newborn Screening and Treatment
3. Collection, Coordination, and Transfer of Information; Research

Perinatal

1. Adolescent Pregnancy
2. Prenatal Care
3. Perinatal Care Network
4. Alcohol, Drugs, and Smoking during Pregnancy
5. Low Birth Weight Infants

Early Childhood

1. Identification of High-Risk/Handicapped Infants and Children
2. Services for High-Risk/Handicapped Children Birth to School Age
3. Lead Poisoning in Children
4. Childhood Illness and Accidents
5. Child Neglect and Abuse

Administrative, Philosophical, and Other Issues

1. Coordination of Prevention Services
2. Coalition Approach
3. Professional Education and Research
4. Ethical and Controversial Issues

Genetic Screening and Counseling

In Virginia, most genetic screening and counseling services are provided through the three medical schools, University of Virginia School of Medicine, Medical College of Virginia, and Eastern Virginia Medical School, at their main facilities and in satellite clinics. While the services offered by these centers are well-established, they do not yet begin to reach large portions of the population that might benefit from such services. Individuals living in areas of the state at a distance from one of the medical centers or satellite clinics and those who do not have a private physician are much less likely to seek or receive genetic counseling and screening.

In many instances, genetic evaluation permits individuals who would have hesitated to attempt pregnancy to go ahead because they know the likelihood of conceiving an infant free from genetic disorders. In the majority of cases antenatal testing also reveals the absence of abnormalities. In 1980-1981, the three Virginia medical schools tested fluid from 954 amniocentesis samples. Of these samples only 20 (2 percent) showed abnormal chromosomes and only 14 (1 percent) showed the abnormal alpha-fetoprotein levels associated with neural tube defects.

According to the March of Dimes, genetic counseling is sought most often by parents with one child who has birth defects. It is also sought, but with less frequency, by those with a family history of abnormality, those from high-risk ethnic or racial groups, and women over 35. In general, the public needs to be better informed about the kind of answers that genetic screening and counseling provide and about when it is important to seek these services.

Recommendations

1. There must be a dramatic expansion in professional preparation and inservice training programs concerning genetic aspects of developmental disabilities and their prevention. Such training should focus on developmental disabilities service personnel, but should include private health care professionals, public health care providers, children's services providers, and the educational system as well.

2. The Department of Mental Health and Mental Retardation should establish genetics associate positions at each of the training facilities to coordinate and expand genetic case ascertainment and follow up, including services to community programs.

3. The capacity for outreach of each of Virgnia's three genetics counseling programs should be expanded by additional positions and other resources.

4. Public education programs about genetic risks and preventive services emphasizing a partnership of public and private resources should be greatly expanded and focused on high risk groups.

5. Funding should be made available to the Health of Department to add an appropriate public health administrator position to help guide the increased genetics services called for in this agenda.

6. Appropriate agencies should support submission of a grant for federal funds to establish genetics services linkages to Virginia's 30 to 40 family practice centers, beginning perhaps at first with a pilot effort at five centers.

7. Genetic services have traditionally been delivered through academically oriented tertiary care facilities and their outreach clinics. Until genetics becomes an integral part of the practice of every physician, its full potential for disease prevention and presymptomatic diagnoses, not only of pediatric diseases but also of chronic illness of adult life, will never be realized. To this end, we propose a pilot study to test the effectiveness of the introduction of a trained masters-level genetic associate into a small number of existing family practice groups to test the effectiveness of the systematic collection of family history for high-risk screening and disease prevention in real world practices.

Newborn Screening and Treatment

It is possible to identify certain genetic disorders, many of which cause developmental disabilities, through screening of infants at or near birth. Many of these conditions involve metabolic disorders, the effects of which can be prevented or reduced in severity by intervention with dietary or other measures.

Perhaps best known among these metabolic disorders is phenylketonuria (or PKU). Since the advent of a simple test of a blood spot on filter paper, developed by Dr. Robert Guthrie, PKU and other metabolic disorders (such as congenital hypothyroidism, galactosemia, homocystinuria, and maple syrup urine disease) can be easily identified and often successfully treated. Other conditions are being discovered which are amenable to this kind of screening (e.g., vitamin deficiency disorders).

Generally, Virginia's newborn screening programs are now considered adequate with the screening for additional metabolic disorders mandated by the 1983 General Assembly.

Recommendations

1. An improved program is needed to identify and maintain contact with females treated for PKU to advise them that they must resume dietary restrictions prior to pregnancy to prevent mental retardation in their children.

2. Legislative mandate and funding is needed to ensure adequate follow up and treatment of metabolic disorders to be added to Virginia's screening program on July 1, 1984.

3. Screening programs for newly identified disorders (e.g., biotin deficiencies) should be piloted as soon as practical and then added to Virginia's screening program.

4. Patients identified in newborn screening programs should be entered into the proposed genetic services registry.

5. Support an interagency study on long-term effects of PKU (and other disorders) in cases screened and treated, to focus on learning disabilities and psychiatric problems.

6. Examine the need for closing gaps in screening programs caused by home births, particularly in rural areas.

7. Support research at Virginia's genetic centers into development of screening programs for storage diseases.

8. Virginia should implement a statewide sickle cell anemia screening program.

9. The desirability of screening newborns at 36 to 48 hours of age should be studied.

Collection, Coordination, and Transfer of Information

In addition to continued research into methods of preventing genetic causes of developmental disabilities, much more information is needed about the incidence and prevalence of genetic disorders. A system that links data collection, analysis of correlations of demographic data, and services to affected families would add much to our knowledge and to prevention strategies. Thorny issues of privacy, ethics, and civil liberties make this an area for careful consideration.

Recommendations

1. A study should be commissioned to identify the legislative changes necessary, yet acceptable ethically to all parties, to expand the current Birth Defects Registry. Legislation mandating a Birth Defects Registry should include requirements for agencies to report the cases that they identify.

2. The Birth Defects Registry should be expanded to include more cases of genetic disorders, including those identified after than birth. A system for easily transmitting this information from physicians to the registry should be in place.

3. A system for linking the individuals identified for the Birth Defects Registry with follow-up services should be established. The Birth Defects Registry should make statistical information about the incidence of genetic disorders available to appropriate agencies and organizations.

4. The Birth Defects Registry expansion should be re-titled along more positive, service-emphasizing lines.

5. Current research into the feasibility of developing programs for prevention of fragile X syndrome, neural tube defects, and vitamin-responsive diseases should be continued and expanded.

6. A special fund should be established by the General Assembly to allow Virginia's genetic centers to conduct special cytogenetic testing for counseling and research into identification and prevention of genetic disorders (many such procedures are not now reimbursable to the centers).

7. Virginia needs to develop mechanisms for licensing laboratories engaged in genetic disorder diagnosis to assure quality control in testing and to improve the likelihood of treatment for cases identified by screening.

8. We call upon the General Assembly to increase the total level of state support devoted to research by a factor of three and to distribute the funds to the major research institutions in proportion to the amount of total external research support that they generate. This proposal will capitalize upon existing peer review mechanisms to determine the allocation of funds and take the legislature out of the business of trying to judge the scientific work of specific research projects.

9. We are concerned that the proposed establishment of a Center for Innovative Technology may actually decrease the level of support available for research at state institutions for higher learning. At some institutions, funds derived from grant overhead have been reinvested in the departments that generate these funds, and this practice has resulted in a spectacular growth in additional external support. We are very concerned about the adverse effect that the diversion of grant overhead funds to the proposed center for Innovative Technology might have upon existing programs of excellence. We therefore propose that the establishment of the proposed Center be accompanied by a requirement that at least 50 percent of grant overhead funds be returned to the department that generated them.

Adolescent Pregnancy

Pregnancy during adolescence is a widespread phenomenon that frequently causes physical difficulties for the mother and child during the pregnancy, labor, and delivery period and often has negative consequences for mother and child for the rest of their lives. Often social and economic problems accompany the physical difficulties of adolescent pregnancy, particularly when the birth is out-of-wedlock. In Virginia in 1980, 5.8 percent of all live births were to women below the age of 18.

Adolescent women, especially very young adolescents, are not physically mature enough for healthy, normal pregnancies. They are at risk for low birthweight infants, premature deliveries, stillbirth, spontaneous abortion, and neonatal mortality among other complications. In 1981 in Virginia, 59 percent of the births that involved complications were to adolescent mothers. The risk of physical problems for adolescent mothers and their children are heightened because nearly half of the pregnant adolescents do not seek prenatal care during their first trimester and often wait until their third trimester. The complications most common in adolescent pregnancy, such as low birthweight and prematurity, may have long-term consequences for the infant including mental retardation.

It is not clear how best to reduce the rate of adolescent pregnancy. There is considerable evidence that many adolescent men and women do not use contraceptives, frequently because of lack of information or access. There is also some evidence that negative social pressures, including a sense in some young women that having a baby is the only worthwhile thing that they can do, contribute to the large numbers of adolescent mothers.

Whatever efforts are made to reduce the rate of adolescent pregnancy, care should also be taken to ensure that a nonjudgemental support system of prenatal care and education is available for those young women who do become pregnant.

Recommendations

1. The Family Life Education Curriculum Guidelines developed by the Virginia Departments of Education and Health should be implemented in every school system. Local school boards determine whether that curriculum will be used and it is not currently used in many school systems. It is especially important that young men and women learn about contraception, human development, the responsibilities of being parents, and how to say no.

2. Contraception and pregnancy testing should be available to every sexually active individual regardless of age.

3. Mechanisms for involving PTOs, church groups, and other concerned adults should be included in local public education efforts.

4. Pilot programs, such as Better Beginnings for Virginia's Children and the Norfolk Adolescent Pregnancy Prevention and Services Program, should be expanded and financially supported by all the agencies involved. Prevention efforts should be evaluated in order to determine effective approaches to the problems adolescent pregnancies.

5. Teenagers need to be instructed in the realities of childraising. Exposure to normal children (siblings, babysitting) should be balanced with planned visits to hospitals or schools where there are handicapped or chronically ill children.

6. Because sexually transmitted diseases can result in premature births, stillbirths, or infected neonates and because pregnant teenagers do not always continue with the same partner throughout pregnancy, thorough screening for sexually transmitted diseases (gonorrhea, chlamydia, syphilis, herpes) should be done early in pregnancy and repeated whenever there has been a new partner or symptoms suggesting infection appear.

7. In addition to prenatal care, management of teenage pregnancy should include involvement of significant others, follow-up, and family planning information.

8. The information included in family life education curricula should be updated frequently.

9. Longitudinal studies should be undertaken to determine whether students who had the benefits of family life education applied the lessons of the curricula.

Provision of Early and Appropriate Prenatal Care

Prenatal care is one of the most significant factors affecting the outcome of a pregnancy. While most women receive at least some kind of medical attention during pregnancy, many women do not seek medical evaluation early in their pregnancy and/or they do not know how to gain the most benefit from their prenatal care. The earlier in her pregnancy that a woman seeks medical attention, the earlier she can be identified as at risk for problems or complications and the more time there is to develop strategies for care.

Good prenatal care encompasses many factors. Sound medical advice plays an important part, but ultimately women themselves have the responsibility to seek medical attention, to ask questions of their care providers, to follow medical advice, and to behave in ways that will contribute to a healthy pregnancy. At a minimum, women need to know about the physical changes that accompany fetal development, the nutritional requirements of pregnancy, and the kinds of substances that are harmful during pregnancy and must be avoided. The more that women understand about pregnancy and about what constitutes good prenatal care, the more actively they can contribute towards a positive outcome of their pregnancies.

Recommendations

1. Information programs to educate women about pregnancy should be made available throughout Virginia. In addition to stressing positive health behaviors, such programs should explain why medical attention is important early in pregnancy and what to expect during medical examinations. Consumer education programs should be undertaken by a broad range of organizations in an attempt to supplement and reinforce the messages given by the medical community.

2. Consumer education programs should focus first on women from high risk populations, e.g., teenagers, low income. Groups undertaking prenatal care programs should include the medical community in their outreach efforts so that there is free sharing of information between the nonmedical and medical communities.

3. A program is needed that will pay for normal delivery and newborn care for indigent women. Medicaid is one, but only one, possible source of funds.

4. Consumer education for both men and women should begin by at least junior high or middle school in order to form attitudes and a "mind set" regarding their responsibilities in the formation and raising of the next generation.

5. Premarital testing for rubella immunity (followed by an immunization program prior to pregnancy) should be studied and initiated if feasible. The need for an expanded rubella immunization program (preschool and teenage girls) and measles immunization program (preschool) should be evaluated.

6. There is a need for continued funding support and expansion of programs that improve the nutritional status of pregnant and recently delivered women (e.g., WIC).

Perinatal Care Network

Perinatal care services are the prenatal, delivery, and newborn care provided to pregnant women and their infants. While the full range of perinatal care services is available in most parts of Virginia, there is currently a lack of coordination at the local and state levels for the provision of these services. As an example, while most local health departments offer routine prenatal care, none offer labor and delivery services. This means that as the time of delivery approaches the pregnant woman must find a new health care provider. A formal arrangement for the continuity of care for pregnant women needs to be developed. Without such formal arrangements, the current situation of women arriving at hospitals in labor, without any medical records, will continue to be a problem.

A perinatal care network is especially important for those women identified as high-risk maternity patients. Such women require the kind of care and consultation that is best provided by regional perinatal care centers. The development of a system of designated perinatal care centers is a step towards the reduction of Virginia's infant mortality rate, which is currently higher than the national average. (1981 Virginia ranked 32nd in infant mortality rate).

Recommendations

1. The Department of Health should continue to support and strengthen designated regional perinatal centers which meet the criteria adopted by the Board of Health, including the responsibility for coordination of education, transportation, and consultation in their respective regions.

2. Comprehensive perinatal care concept should be extended from conception through the first year of life with particular emphasis placed on securing appropriate services for high-risk maternity patients who do not currently seek early prenatal care. Funding must be sought so that no woman is denied services because of an inability to pay.

3. Perinatal health care facilities are encouraged to develop their capabilities as suggested in the Statewide Perinatal Services Plan.

4. Health care providers should encourage the transfer of high-risk mothers to appropriate facilities prior to delivery and should encourage the transfer of infants back to their local hospital as soon as possible after the acute phase.

5. Social and other family support services are an essential part of the care provided by perinatal health care facilities and must be available to each family served by the facility.

Alcohol, Drugs, and Smoking During Pregnancy

There is evidence that heavy consumption of alcohol, use of some drugs, or heavy smoking can have deleterious effects on the developing fetus.

Essentially all the cases of fetal-alcohol syndrome (a series of symptoms including growth retardation, central nervous system damage, and facial abnormalities) that have been identified prospectively have occurred in women who by most acceptable criteria are chronic alcoholics, i.e., alcohol dependent. Further, there is evidence that the lion's share of the damage is probably incurred by fetuses of the heaviest and/or most frequent drinking 3-5 percent of women - at most of about 10 percent of women who drink. In other words, alcohol-related birth defects are probably concentrated in a relatively limited proportion of pregnancies marked by abusive drinking. While more research is needed, it does appear that women, even abusive drinkers, who are able to decrease their drinking or stop their drinking during pregnancy have healthier infants than those who do not.

Women who are heavy smokers may also have problems during pregnancy. These women are potentially at risk to have low birthweight babies, to have preterm deliveries, or even to have stillbirths or infant deaths during the first week of life. Unfortunately there is evidence that pregnant women, particularly heavy smokers, often have very little success in modifying their smoking habits.

Pregnant women should consult with their health care providers about the risk of taking specific drugs, including over-the-counter medications, while they are pregnant and about the effect that other potentially teratogenic substances could have on their babies.

Recommendations

1. There is evidence that the most effective means to modify the drinking habits of alcohol abusing women is through contacts with health care providers, particularly in the prenatal clinic. There is a need for professional education programs aimed at teaching health care providers methods of identification of the alcohol abusing woman as well as initial intervention approaches.

2. Although prevention strategies might most effectively focus on substance abusing women, all women should be informed about the potential danger of excessive use of alcohol, drugs, or smoking

during pregnancy. Because many teenage girls drink and/or smoke regularly and may not be aware of pregnancy or may deny its presence for weeks to months, efforts should be made to decrease use of alcohol and cigarettes by all teens. Programs that help all women stop smoking and drinking should be available.

3. Virginia should establish a Teratogen Registry and Hotline, modeled on that of San Diego, to offer health professionals and pregnant women advice on the probable effects of substances on pregnancy and to collect data about the effects of substances on the outcome of pregnancies.

4. Alcoholic beverages should carry a label that warns of the dangers of alcohol-related birth defects in the children of women who abuse alcohol. Similar notices should be posted in places where alcoholic beverages are sold.

Low Birthweight Babies

Infants having low birth weight (5 lbs. 8 oz. or less), whether born preterm (less than 37 weeks of gestation) or merely small for date, may face a host of difficulties. Low birthweight is a factor in most newborn deaths under one week. Those low birthweight infants who do survive are more likely to have health and developmental problems, including mental retardation. The number of low birthweight infants born in Virginia each year is unacceptably high. In 1981 the low birthweight rate for infants born in Virginia was 74 per 1000 live births.

A number of factors may contribute to low birthweight. There is a strong correlation between birthweight and the number and the time of initial prenatal care visits, with lower birthweight associated with little or no prenatal care. There is also evidence that maternal habits, including consumption of alcohol, improper nutrition, and smoking contribute to the risk of having a low birthweight infant. Infants who are born preterm frequently have low birthweight. The causes of birth before full term include premature rupture of membranes, preterm labor, and maternal-fetal problems such as multiple pregnancies, hypertension, and congenital malformations. Early identification of women at risk for preterm delivery and general counseling of positive health behaviors during pregnancy are current strategies for prevention of low birthweight infants.

Recommendations

1. All women should be screened for risk of preterm births at the initial prenatal visit and again at approximately 26 weeks. Cervical evaluation at the 26th week screening is valuable. All women should receive education focusing on the signs of preterm labor.

2. The Department of Health should continue to fund pilot preterm birth prevention programs in Virginia. Such programs can identify women at risk for preterm delivery and offer appropriate treatment and follow-up.

3. Efforts should be made to collect data on the effectiveness of preterm delivery prevention programs - both the programs established by the Department of Health and independent efforts. Strategies that are evaluated as most effective should be duplicated on a wide scale.

4. Women should gain adequate weight during pregnancy (24 to 26 pounds). A weight gain graph is helpful. All pregnant women and particularly mothers at risk for preterm birth should receive nutritional counseling. Programs, such as WIC, that help low-income mothers improve their nutritional intake should be supported through increased funding.

5. In an effort to reduce the potential for further complications, adequate medical treatment, including transportation to regional perinatal centers and return to local hospital as soon as possible, should be available for low birthweight infants.

6. Teamwork is an important component of any preterm birth prevention program. Effective program teams include, but are not limited to, physicians, nurses, social workers, information coordinators, data analysis consultants, and pregnant women.

Identification of High-Risk/Handicapped Infants and Children

Infants and children at risk for developmental delays must be identified as early as possible if they are to receive maximum benefit from special services. Identification can be a complex task since developmental delay may be caused by physical, environmental, or combinations of several factors that have greater or lesser significance over time as the child ages.

Identification implies both an active search for the developmentally delayed and a system for linking those in need with appropriate services.

Recommendations

1. Comprehensive evaluation and follow-up should be provided for every child leaving a neonatal intensive care unit since that group is at extremely high risk for developmental delay.

2. A valid developmental screening tool should be widely available and implemented for the routine periodic screening of young children done by public health personnel, local physicians, social service workers, and child care staff. Distribution of the screening tool should be accompanied by basic training in its use or, at a minimum, information listing a source to contact for questions or referrals.

3. The criteria for identifying a child as high risk or handicapped should be carefully developed and should be uniform throughout the state. Personnel who use the criteria need to receive training. Children should not be labeled as mentally retarded unless a comprehensive assessment of mental ability, physical health, and adaptive behavior demonstrates a handicap severe enough to justify the designation.

4. In order to assure continuity of services, children from birth to age 2 who are identified as potential candidates for special education should be referred to their local public school division so that the school can institute an evaluation.

5. Medical management should be a component of the infant stimulation and preschool programs for high-risk/handicapped infants and children.

6. Criteria for identifying children at risk for vision and hearing loss should be refined. Children identified as at risk should receive thorough examinations.

7. A system of universal screening of children for developmental abnormalities should be implemented at all "well child centers" at which children congregate (e.g., day care centers). Of necessity, obviously, is training for all staff of such programs in understanding and recognizing developmental delay indicators.

8. A program of systematic diagnosis, classification and screening of early childhood seizure activity must be incorporated into early childhood evaluation and follow-up procedures.

Services for High-Risk/Handicapped Children Birth to School Age

There is a pressing need in Virginia for a comprehensive, coordinated system of services for high-risk/handicapped children from birth to school age. Currently state statutes mandate that services be available, through the public school system starting at age 2, for those children designated eligible for special education. Although many localities offer some kind of early intervention program for children below age 2, these efforts are piecemeal. Virginia lacks clear standards for early intervention programs and official designation of the agencys or departments responsible for provision of these services.

Recommendations

1. The General Assembly should mandate a comprehensive and coordinated service system for identifying and serving handicapped/high-risk children that is available from birth. This system of services should be provided by a variety of agencies, but a lead agency should be designated for planning purposes. Services can be provided by agencies currently in existence in communities, but they must coordinate their efforts and follow consistent guidelines.

2. The General Assembly should, at a minimum, authorize a study of the need for coordinated and comprehensive services for handicapped/high-risk children beginning at birth.

3. Virginia needs a statewide network for parents of high-risk/handicapped children. With assistance from a coordinating office, parents could learn how to work with their children and could form groups for support and information sharing. Such a network might also encourage parents to see that the services their children need are utilized. Creation of such a network is recognition that the families of high-risk/handicapped children need special services and attention.

4. Provision of services to high-risk/handicapped children would be enhanced if a formal group existed to identify gaps in services and to monitor program effectiveness. A subset of the interagency coordinating committee established by the General Assembly is a possible group to serve this function.

5. A Virginia-based longitudinal study to prove the effectiveness and cost efficiency of various early intervention techniques should be funded and implemented immediately.

6. Programs that currently are being used to stimulate cognitive development in young children should be encouraged and expanded.

7. All early intervention programs must emphasize extensive family and other support group services, as these systems are, by far, the predominant influence on development.

8. In perhaps no other area is the need for interagency coordination and the elimination of "turf-ism" more critical for successful intervention on family, neighborhood, and community systems.

Lead Poisoning in Children

Lead poisoning, often called an insidious problem because its effects are not apparent until irreparable damage is done to the central nervous system, is a completely preventable cause of mental retardation. Lead poisoning is easily detected in a simple test using a drop of blood from a finger prick. Blood samples (tested for protoporphyrin) can be analyzed immediately with portable equipment.

Children absorb lead when they eat chips of lead-based paint, breath air that is contaminated by automobile or industrial exhaust, eat or drink from improperly prepared containers, or simply put their hands in their mouths after they have played indoors or outdoors in areas containing lead dust. While risk of lead poisoning is especially high in neighborhoods built prior to 1950, recent research indicates that the prevalence of lead risk is far greater than previously thought, extending beyond "high-risk" areas into middle and upper-income rural and urban areas. The solution to the lead poisoning problem requires both elimination of environmental hazards and screening with follow-up treatment for all children.

Recommendations

1. Each child in Virginia should be screened for lead exposure at age 2, or earlier if high risk. Children living in areas with high risk for lead poisoning should be screened annually until age 6. Screening for lead exposure should be a mandated element of the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) program. A system of follow-up for all identified cases must be in place.

2. Localities should develop ordinances that permit inspection for lead paint before property is rented. Currently most localities permit rental property inspection only after a case of lead poisoning is identified. Many localities have no ordinance in place regarding lead hazards. The penalties for failure to remove lead paint must be stringent enough to ensure that repairs will be made and made expeditiously.

3. Regional laboratory facilities, capable of analyzing large numbers of blood samples and paint samples, should be identified or developed by the Division of Consolidated Laboratories. Regional centers should include staff that can offer outreach and training to local medical personnel. These centers should be located geographically so as to be immediately responsive to the population served.

4. Community education is essential for the elimination of the lead poisoning problem. Parents need to understand why children who show no symptoms need to be screened and may need treatment. The general public needs a clearer understanding of the broad nature of the problem and how lead hazards can be removed. Realtors and property owners require enlightened understanding of how the problem occurs. The voting public needs to understand the huge financial costs incurred by failure to achieve a workable, statewide lead poisoning prevention program.

5. Consideration should be given to increasing the lead screening program called for in recommendation number 1 in this section to annual screening of all children prior to age 5.

6. The FEP test (filter paper blood spot) could be used in place of the current hematocrit test, as it will serve to identify both lead poisoning and iron deficiency anemia (which is currently commonly screened around age 2).

7. Leaded gasoline should be banned in Virginia. Failing this, sale at self-service pumps should be eliminated to reduce illegal use in cars with catalytic converters. If leaded gasoline cannot be banned, it should be taxed to the price level of lead-free gasoline and the revenue dedicated to lead screening programs.

Childhood Illness and Accidents

Damage to children caused by illness and accidents accounts for many instances of mental retardation. Studies indicate that as much as 2 to 5 percent of mental retardation can be linked to traffic accidents, head injury, and accidental poisoning. In addition, as many as 25 percent of the children with congenital rubella syndrome, children whose mothers had German measles while pregnant, are mentally retarded or have other developmental disabilities. Similarly about 33 percent of the children who develop measles encephalitis, a serious complication of Red measles that occurs in 1 in 1,000 cases of measles, become mentally retarded. In most cases, developmental disabilities caused by childhood illness and accidents never had to occur. There are preventive actions that can be taken to eliminate these hazards.

Vaccines against both German measles (rubella) and Red measles (rubeola) have been available for some time. Rates for immunization of children vary over time, but are helped because immunization must be documented before children can attend public school. Two major problems today are the number of women of child-bearing age who are not immune to rubella (15 percent of that population) and the number of young children who are never immunized against either type of measles or who do not receive immunization until they are school age. Rubella and Red measle epidemics will continue to be a danger as long as large numbers of children and women remain susceptible.

The leading cause of head injury in young children is automobile accidents. Other significant causes are automobile accidents involving pedestian children, falls from windows, and falls on playgrounds. Compliance with Virginia's child auto restraint law would be a giant step towards reducing the developmental disabilities that follow head trauma.

Poisoning, particularly by carbon monoxide, and near drowning are other childhood accidents that can contribute to mental deficiency. In addition to education to reduce the risks of these hazards, the public needs to learn to seek medical treatment immediately in the event that an accident does occur.

Recommendations

1. The Virginia child automobile restraint law must be enforced. Police officers need to be educated about the importance of child car seat restraints so that they will at least issue warnings, if not tickets, for violations of the law.

2. There is a pressing need for increased public funding of car seat loaner programs--particularly for toddler seats. Car seat loaner programs are also an excellent way for the private sector to become involved in prevention activities.

3. Emergency medical care personnel need training to handle pediatric emergencies. Every rescue squad should carry pediatric equipment.

4. The law requiring immunization by age 2 and proof of immunization before public school attendance must be enforced. Day care centers and preschools should be encouraged to require that their students receive immunizations.

5. The existence of poison control centers at University of Virginia and Medical College of Virginia should be widely publicized across the state. Both centers accept collect calls.

6. A program for the primary prevention of childhood poisonings should reach every family with young children. Primary goals would be increased recognition of poison hazards, ability to quickly access the poison control center, and presence of ipacac or charcoal in each home. This program should also stress the danger of prenatal exposure to toxins in general, and carbon monoxide in particular.

7. Public and professional education programs should stress the high frequency of serious and lethal injuries from submersion.

8. Concrete or other hard-surface play areas should be replaced with wet sand or other more resilient surfaces.

9. Window guards (at a cost of only $3.00 per window) should be installed in all areas frequented by children.

10. Standards for safe swimming pool design, fencing, and operation should be developed, publicized, and incorporated into pool construction and operation standards and licenses.

11. Regional poison control centers should be designated by the Department of Health.

Child Neglect and Abuse

That neglect and abuse are environmental hazards for thousands of young children is unquestioned. The evidence linking physical abuse with developmental disabilities is fairly clear. Studies of severely battered or shaken infants or young children reveal many instances of failure to thrive, brain damage, and below average IQ scores. The relationships between less severe physical abuse, neglect (particularly malnutrition), emotional, and sexual abuse and developmental disabilities are more speculative, although it is assumed that abused or neglected children are at greater risk for developmental delay and possibly permanent disability.

Considerable debate centers around the most effective strategies for working with neglected or abused children and their families. A necessary element for any strategy is that suspected cases of neglect or abuse be reported to appropriate agencies. Among other strategies are parent support groups, counseling of individual family members or families, and separation of children from their abusing parents. The most promising prevention strategy may be parenting skills education for all young people long before they actually become parents. Parenting education can help perspective parents prepare for the stresses of raising children and make them aware of situations during which they may need outside support.

Recommendations

1. Individuals who work with children, particularly day care providers, teachers, and health care providers need training so that they can pick up the indicators of child abuse and neglect as early as possible. These groups also need to be familiar with the law that requires certain individuals who work with children to report suspected cases of neglect and abuse to child protective services.

2. Abusive parents require treatment. Professionals who offer such treatment need specific training about family dysfunction and the cyclic nature of abuse.

3. Education in parenting skills is necessary, not just for those who have children, but for young people before they become parents. Education in parenting skills should be a mandated part of the curriculum for family life education.

4. Virginia needs a better, more comprehensive system for temporary foster care.

5. All efforts in child abuse prevention must be guided by current understanding of individual and family behavior and dynamics, involving the widest possible range of interdisciplinary and interagency support.

6. Research into the early identification of indicators for high risk of dysfunctional parenting patterns should be supported and pilot programs initiated.

7. Child abuse and neglect reporting requirements should be extended to all groups, including clergy and the legal profession.

School Age Children

We believe it is still possible to engage in primary prevention with school-age children who are at risk of being mislabeled as "mildly mentally retarded" (or "functionally mentally retarded").

Following the recommendations of the Panel on the Selection and Placement of Minority Children in Special Education of the National Academy of Sciences, we would make the following recommendations to prevent misdiagnoses and to assure appropriate educational programs. These recommendations will have impact not only on the child, but on the families, the learning environment, and the community.

Recommendations

1. Programs should be developed so that children can receive immediate educational interventions as soon as academic problems are identified by the regular classroom teacher. Consultation from special educators, psychologists, resource teachers, and other resource specialists should be made available immediately, without the necessity of referral and labeling.

2. Before a child is referred, at least three distinct educational strategies should be tried to promote academic performance (in consultation with the parent and the resource team). Some of the recommendations are based on empirical studies in other states and have been shown to have reduced the number of referrals by 50 percent.

3. The use of direct instructional techniques, peer tutoring, and the use of cooperative learning techniques that increase the amount of "academically engaged time" should be encouraged.

4. Special educators and regular classroom teachers should be trained in the use of these techniques. This would also require trainers be trained in these techniques.

5. We recommend that model schools be established in several locations in Virginia that would take children who would have been labeled "mentally retarded" using only IQ test scores, but who have been assessed using IQ tests and adaptive behavior tests normed to their own cultural groups, and thus who have been identified as being

within the normal ranges of these groups. The model schools would then seek to demonstrate and to evaluate programs that have been shown elsewhere to be effective in preventing mild mental retardation. The Virginia model schools would select and combine portions of these successful programs that best fit local conditions. Teachers and staff of these model schools should receive training in prevention/promotion, as well as in ethnically sensitive helping, in addition to their basic educational training.

6. Any changes, as necessary, in the present state law which controls special education funding that requires "labeling" for funding to be granted should be made so that recommendations can be applied based on a child's needs rather than on a child's label.

Coordination of Prevention Services

Virginia does not lack any of the major components that are now known to be necessary to reduce the incidence of mental retardation and other developmental disabilities. What is lacking is a means of coordinating the planning and delivery of services and a means of evaluating the gaps in services. That every component exists in some form somewhere in the state does not imply that services are widely available. Many prevention activities, e.g., preterm birth prevention, adolescent pregnancy prevention, are still in the pilot project stage. Other activities, e.g., genetic screening, infant development programs, are available in some localities but not in other parts of the state and many such programs are understaffed. One of the keys to reducing the incidence of developmental disabilities in Virginia will be to increase the accessibility of prevention-oriented services.

Another problem is the result of the number of agencies that need to be involved in systematic prevention efforts. A child at risk, for example, might require health, social, and education services. Too often the agencies involved fail to produce one coordinated plan for services. Instead the services might be offered in a piecemeal fashion. A system that rewards interagency collaboration in prevention efforts is missing in Virginia.

Virginia also needs a mechanism for sharing information about prevention with other states and with the federal government. Prevention activities are becoming more common in all parts of the country. A system of information exchange can help eliminate duplication of pilot projects and boost effective programs. Virginia can perhaps enhance the use of its prevention resources through active contact with federal agencies and other state agencies.

A final area that needs to be included in coordinated prevention activities is the private sector. Private practice physicians, for instance, are a segment of the private sector that is essential for many prevention efforts. Outreach is necessary to inform physicians of the services that are available, to encourage them to refer their patients to appropriate services, and to encourage them to submit the kind of statistical data that can measure the effectiveness of prevention activities. The increased involvement of private practice physicians, especially obstetricians, gynecologists, pediatricians, and family practitioners, is necessary for Virginia to have a true network of prevention services that are available to every citizen.

Recommendations

1. A dramatic improvement in interagency consistency in identification and classification of developmental disabilities is a necessary precursor to establishment of improved incidence and prevalence data, a baseline for measuring the effectiveness of prevention efforts.

2. The General Assembly should create a Joint Legislative Commission for MR/DD Prevention with members appointed by the governor and with a sufficient budget provided to carry out its charge to coordinate state agencies and other organizations in the implementation of the MR/DD Action.

3. The governor should appoint an interagency coordinator of MR/DD prevention services who has the authority to coordinate relevant activities of state agencies and to represent Virginia's prevention efforts to other states and the federal government.

4. The Mental Retardation Advisory Committee of the Virginia Department of Mental Health and Mental Retardation should increase its focus on prevention activities and should work closely with the statewide advisory committee on prevention.

5. The Genetics Advisory Group and the State Perinatal Services Advisory Council should expand their prevention advisory responsibilities to include the Departments of Mental Health and Mental Retardation, Education, and Rehabilitative Services.

6. The Developmental Disabilities Planning Council should continue to provide leadership in promoting coordinated planning and implementation of prevention activities. Developmental disabilities funding should continue to provide support for demonstration projects and initiation of local and statewide prevention coalition activities.

Coalition Approach

Because interest in prevention of mental retardation and other developmental disabilities cuts across many disciplines, individuals from a variety of organizations and agencies should be involved in prevention activities. Coalitions are one way to harness energy and expertise from a variety of sources. The range of experience that a coalition can collect is particularly well-suited to prevention activities because prevention is a complex undertaking that has many facets.

A two-tiered approach, using numerous local coalitions and one statewide coalition, is perhaps the best strategy for stimulating prevention activities in Virginia. Coalitions exist in a number of localities already. These coalitions generally work on public education campaigns highlighting some aspect of prevention. A few examples from recent local campaigns in Virginia include an attempt to encourage a local school system to add a family life education curriculum, a campaign to encourage mothers to seek early prenatal care, a campaign describing the new child auto restraint law, and a campaign to inform adolescents about where to seek contraceptive information and how to make responsible choices about sexuality. Because public education is a key to successful prevention programs, community-based efforts are especially important. Local groups have the best sense of the needs of their community, or can develop that sense, and can tailor their message to most effectively meet the needs of their community.

There is also a need for a statewide prevention coalition. The kind of strength-in-numbers that coalitions can project is important for lobbying and related activities that determine the use of resources. In addition a statewide organization that is well represented immediately increases knowledge about services and lack of services in different regions of the state. Finally a statewide organization can work to see that prevention of developmental disabilities remains a priority for Virginia and can offer support to local prevention efforts including local coalitions.

Recommendations

1. The 1983 Virginia Mental Retardation/Developmental Disabilities Prevention Conference should endorse the formation of a statewide developmental disabilities prevention coalition. The first meeting of this coalition should be held by early spring 1984.

2. One function of the statewide prevention coalition should be to promote the development of and to offer support to local prevention coalitions. Statewide efforts such as the Better Beginnings for Virginia's Children coalitions should also be encouraged and expanded.

3. One function of the statewide prevention coalition should be to present an annual award or awards for prevention activities and to utilize this as a mechanism to heighten public awareness of prevention.

4. Funds to maintain the statewide prevention coalition should be solicited from a broad base of organizations.

5. Caution must be observed in coalition formation to keep activities focused and action-oriented.

6. The statewide coalition should implement systematic public awareness campaigns and provide resources and technical assistance to local coalitions for local public/professional education activities.

Professional Education and Research

Medical, social service, and special education programs often offer their students very little information about human development and even less information about prevention or amelioration of developmental delays and disabilities. Educating professionals about prevention of mental retardation and other developmental disabilities is a doubly beneficial action. In addition to using the information in their own work, professionals are frequently in positions that permit them to pass such information to the general public.

Prevention techniques and strategies are constantly evolving. Much more research is needed on the effectiveness of current prevention efforts and on public information techniques. In addition, research that might lead to scientific breakthroughs must be supported and the results widely publicized. A professional community in which there is widespread general knowledge about prevention is much more likely to devote research time and energy to furthering knowledge about prevention.

Recommendations

1. Programs for educating physicians, nurses, social workers, psychologists, teachers, guidance counselors, and other professionals who work with children and families should include a prevention of mental retardation and other developmental disabilities component. Professionals who will work with high-risk/handicapped children and their families need practical experience working with these groups as a part of their training.

2. The curriculum for educating those who work with children and their families should acknowledge that high-risk children include not only the handicapped but also children from social, cultural, ethnic, and economic backgrounds different from the so-called norm. Training in cultural pluralism should be incorporated into all professional curricula and inservice training programs utilized for relevant administrators and service providers involved with prevention programs and activities.

3. The Virginia Department of Mental Health/Mental Retardation should form a Prevention Research Council to exchange current information, coordinate, and stimulate research in prevention and public information techniques.

4. Schools of higher education should not only incorporate principles of prevention into relevant curricula but should become actively involved in state and local coalition activities.

Ethical and Controversial Issues

Although prevention of developmental disabilities is a positive goal it is not without controversy. A number of issues can be raised in conjunction with prevention activities. In some cases issues can be resolved by simply making clear what the purpose of the activity is--for example stressing prevention of disability rather than prevention of disabled persons.

Some issues are not resolved simply by explanation but require policy decisions. Commitment of resources is an example of this type of issue. When resources are limited, hard choices, such as whether to fund services for the disabled or to use the funds for prevention programs, must be made. Since these questions are not strictly either/or, some effort is required to weigh the needs of the current generation against the interests of future generations. Advocates of prevention have a responsibility to offer guideance to policy makers to help them make these decisions.

Some of the issues associated with prevention activities raise fundamental questions about rights. In some cases, the question is how far to go to prevent disability. Antenatal screening, as an example, sometimes reveals abnormalities that can only be prevented through termination of the pregnancy. The issue becomes whether the fetus has a right to life even if that is not the desire of its parents. A somewhat related question asks how extensive medical treatment should be given to seriously ill and potentially disabled infants. Does society have an obligation to protect the rights of newborn infants or to protect the privacy of their families. Clearly prevention can be associated with issues that stir heated debate.

It is important to stress that there is no single stance that everyone who is committed to prevention accepts. All advocates of prevention do not consider abortion an option. All advocates of prevention do not support federal intervention in decisions about medical treatment. Advocates of prevention bring their personal values to their work and these values determine individual reaction to ethical questions. As long as there is controversy about some aspects of prevention the best strategy is to encourage individuals to understand the basis of their feelings and the implications of their decisions through an open discussion of the issues.

Recommendations

1. Individuals who participate in prevention activities should be aware of the sensitive issues such activities may raise. Activities to promote values clarification and sensitivity training should be encouarged.

2. Any language used in describing prevention activities should be developed in such a way that it does not reinforce stereotypical images of persons with disabilities. Persons involved in prevention activities must consciously avoid using terminology which devalues handicapped persons.

3. The public in general, and health care professionals in particular, need more education about the ability of persons with disabilities to live fulfilling lives. Greater contact between persons with disabilities and those without disabilities would benefit both groups. Public education must focus on improving public attitudes and perceptions about disabilities.

4. More work needs to be done to improve the ability of the medical profession to make accurate assessments of the longevity and potential for self-direction in infants born with severe disabling conditions. Data concerning long-term outcomes should be collected.

5. There is little education in or detailed exposure to ethical aspects of pediatric care, especially in areas of high-risk newborns and handicapped children. Training programs should include lawyers/philosophers/ethicists in regular rounds and conferences to discuss such issues with physicians, nurses, and other health professionals both in training and after graduation.

6. Recent publicized cases involving decisions about treatment of severely handicapped newborns suggest that parents may be asked to make a decision based on biased or incomplete information. When parents are asked to weigh the risks and benefits of life-supporting or life-prolonging treatments in the face of severe disability, they should be provided with complete information by the most knowledgable persons, free of bias, and should have the opportunity to meet with parents of similarly affected children who have faced similar decisions or who have experience in raising such a child.

7. Ethical review boards should be established to provide counsel, if desired, to families and professionals involved in critical choices involving cases similar to Baby Doe and Baby Jane Doe. This would serve as a "moral community" to assist and support families and others in the decision process and its aftermath.

Concluding Remarks

By Howard L. Sparks
Conference Chairman

It is our hope that we will conclude today with a plan for Virginia that will serve as a model for other states and eventually a model national plan for prevention.

As chairman of this conference, I have had the privilege and pleasure of presiding over a process which began over a year ago, has involved over 500 people, and will, only in a very small sense, culminate today. In the largest and most important sense, today is just a beginning. Other conferences and other times have culminated in solid plans and documents. That will not be so here. The critical essence of this conference is quite different, but more about that later.

In order to bring you up-to-date, let me review with you, if I may, those steps that have been taken to bring us to this point.

It is impossible to pinpoint the time at which Virginia first became concerned about preventing mental retardation and other developmental disabilities. Out of the glare of public scrutiny and, perhaps, unknown to many of us in this room, Virginia's three medical schools, its departments of health, mental health and mental retardation, education, social services, and its Developmental Disabilities Council, have made steady and important strides toward reducing the incidence of developmental disabilities. As scientific knowledge developed, particularly after the 1960s, Virginia instituted prevention programs as they were judged to be practical and cost effective. In prevention, as in most things, Virginians may not be the first to do something, but we seldom are last. But usually we do it well, and, in many cases, we do it better than almost any other state. Though it may frustrate us, there may be something to be said for a conservative approach to the development of social and public health policy. We must be particularly appreciative of the need for cautious and careful stewardship of public revenues in these days of limited resources.

And that is okay. What is not so okay, for many of us, is the *degree* of caution that we have often shown. But even the most aggressive reformers must admit that, in some cases, patience is a virtue and in all cases, efficiency and economy in government are necessary. Whether we agree with it or not, political reality in Virginia mandates caution and care, not just in these troubled economic times, but as matter of state philosophy and public policy.

These observations notwithstanding, we must point quickly and with pride to Virginia's many carefully constructed and cost efficient prevention programs. Our screening program for PKU and other metabolic disorders is comparable to the best in most states, if not all. Our three centers for genetic counseling are among the leaders of their type in the nation. Our early intervention programs are often used as models for the region and the nation.

Let me not mislead you, however. We all know that in significant areas Virginia lags behind its neighbors in the region and far behind some states of the nation, in its breadth and comprehensiveness of prevention programs. For example, the 1982 report of the state Perinatal Services Advisory Council suggests that we have to go very far indeed to assure that adequate prenatal care, neonatal intensive care, and other health and developmental services are available for every mother and infant. Our infant mortality rate, an imperfect but important measure of overall health care availability and quality, is far higher than it should be under any circumstance. In 1981, our rate was worse than that in 31 other states. You and I know that we have much to do in this area. You will recognize that many recommendations in the Action Agenda echo those of the Perinatal Services Advisory Council.

Examples of Virginia's Progress

From my own personal perspective, I can look to certain events and certain individuals as examples of Virginia's progress and our hope for the future. Many of the program participants here this week in Williamsburg were early pioneers in bringing about prevention to Virginia. One example is Ruth Diggs, and I know that you continue to share my delight with her award of last evening. Other Virginia pioneers who have been active conference after conference and meeting after meeting, are Thaddeus Kelly, Dottie MacConkey, Fred Wirth, Walter Nance, Peter Mamunes, Carolyn Strickland, and Florence Segal. These are just a few of the many people I might cite who have created the 1979 conference and this 1983 conference on prevention.

Activities have come from each conference which have lead to advances in prevention in the Commonwealth. Through their work at this 1983 conference and, of course, their daily work, these pioneers are responsible for much of Virginia's progress to date. In addition to those people I have mentioned, we need to pay tribute to the many physicians,

educators, scientists, public health administrators, public officials, and legislators who have worked hard to obtain needed legislation. There are hundreds of private and public health care professionals who have implemented the new laws, who have improved and refined their programs and techniques to bring Virginia to its current level of effectiveness.

Most importantly, they are joined by thousands of Virginia volunteers particularly through the Association for Retarded Citizens, United Cerebral Palsy, the Epilepsy Foundation, Handicaps Unlimited in Virginia, the Developmental Disabilities Council, and the March of Dimes. In the finest tradition of Virginia's partnership between the public and private sectors, prevention has moved forward increment by increment through collective effort.

As participants in this conference, you have had a difficult but, I hope, rewarding challenge. You have been asked to listen, to learn, to contribute, to develop and to refine. Ultimately we hope you will approve an Action Agenda for prevention in the Commonwealth.

You should know that this charge has been shared with many others who could not be with us today. Each of Virginia's 50 local Associations for Retarded Citizens was provided an opportunity to contribute to the development of the Action Agenda. So, too, was each of Virginia's 40 community service boards. To guide us in our efforts, the broadly based conference planning committee sought national help and consulted leaders across the country. The 62 people who are with us here in Williamsburg as speakers, session coordinators, and moderators, also contributed to the creation of these recommendations. The herculean task of pulling together and continuously modifying the Action Agenda and bringing it to its current draft state, was undertaken by the staff of the Region 10 Community Services Board under the able leadership of Ruth Kavanaugh.

In my 25 years of involvement in the formation of state policy, I have seen the creation of enough documents to fill footlockers laid end-to-end from Richmond to Charlottesville. They too often have little effect and their lonely status is deplored only by their authors.

The Action Agenda

But we are at a different time now. First of all, we have not developed a state plan, we have developed an Action Agenda. It is not an official instrument of state policy. It has not been reviewed and approved by the agencies of Virginia's government. This is both a strength and a weakness. It is a weakness clearly because the agenda may contain inaccuracies, inadequate detail, and lack the fine grooming one might wish to give a formal document for mass distribution. Its strengths, however, far outweigh these relatively minor weaknesses. And chief among its strengths are the commitment and energy represented in each and every recommendation. No editing has taken place. No dilution

of politically sensitive topics has been allowed. What you have is raw and unadulterated and potentially very powerful. It depends upon us.

Another dramatic strength of this document is the fact that it is a beginning and not an end. It is a beginning because we will not say today that this agenda is complete; in fact, this document shall only spawn further discussion and refinement as we go through the process of implementation. All of the groups who were invited to contribute to the agenda will be invited to review it. It will be shared by representatives of every state in the nation to see what ideas and suggestions they can add. It will live and grow as a document until its aims are met.

Let us now review briefly the main elements of the agenda. As each of you registered, you were given a bright green folder entitled "Action for Prevention," and that is about the sixth or seventh draft that it has gone through. This morning you received a seven or eigth page addendum. This addendum corrects, amends, amplifies, and refines the agenda with which you began the conference. It was developed from the suggestions of the speakers and conferees on Wednesday and Thursday and derives solely from the workshops.

What you have then, the basic draft and in addition to the addendum, represents our best current and collective wisdom. One thing is apparent as we look at the list of recommendations. There is no magic pill. There will be no miraculous breakthrough.

Developmental disabilities is a complex assortment of conditions which stem from an extraordinary variety of circumstances. Because of that, the future prevention of developmental disabilities will be made up of many small steps. The recommendations that we have today are just that--a number of small, difficult steps, not one of which would lead to the breakthrough, but each of which would make a significant gain. Collectively, they will move us steadily toward our goal.

Major recommendations

The major recommendations can be considered within the four general areas which we discussed in this conference. Let us review these very briefly.

I. What is needed to prevent genetic causes of mental retardation in Virginia? *First and foremost, the improvement of our outreach capability is needed in identifying cases of developmental disabilities which stem from genetic disorders.* Our current genetic centers need more staff. The entire DD system needs better training around genetic issues. We need genetic services and awareness at every major direct service site. We need to identify how we can obtain the necessary social, racial, economic, and family history data in cases of identified developmental disabilities so that we can begin to fit the pieces of the puzzle together. By so

doing, we could then begin to identify those cases which seem to have something in common, which might stem from genetic causes, which may be predictable and therefore, may be preventable. To do this our data needs are massive. To get those data, we would need major changes in the laws of the Commonwealth and procedures by which we identify and deal with developmental disabilities. It is natural and, indeed, appropriate, that this area raises serious questions of ethics and legality. Americans regard nothing so highly, Virginians perhaps most of all, as our rights to privacy. Consequently, a major study of the ethical and legal problems and opportunities for improving our data collection in case-ascertainment is needed and must be conducted. Also needed in the area of genetics is continued research, both basic and applied. Virginia's medical centers are at the forefront of research in genetic disorders, but their research must be continued and it must be expanded. We must be willing to finance scientific, inquiry which might well lead to answers to some very important questions.

We must also support applied research. We have learned here that screening measures for a number of conditions may be just beyond our reach. Many are already in use in other states and countries. If screening of maternal serum for possible neural tube defects is possible, we must do it. If there are ways to screen for vitamin responsive disorders, we must do it. If there are ways to identify the genetic risk in certain families, we must do that, too.

II. A second major focus of the Action Agenda is perinatal health. Here we attack those causes which occur from conception and delivery. The leading recommendation is that of access and the use of existing perinatal services. We know what good perinatal health care and health practices are, but we must recognize that far too many women do not seek or experience such care.

A major need is to provide funds to low-income women for prenatal care and delivery services. The very women with the highest risk are not eligible under any program t receive care for a normal delivery unless they can pay. This in inexcusable. We cannot tolerate such an obvious gap in services. Whether through Medicaid or whatever means, Virginia must make these services available. There is much that can be done to prevent preterm births. Prematurity, as we have heard throughout the conference, is correlated with low birthweights and risk of developmental disability. A large-scale public and professional education program must be mounted in order to increase the changes, in order to aid in identification of risks for preterm delivery and provide treatment and follow-up in cases of preterm births. Such programs exist and we have heard about them at this conference. They take into account the needs for education and social support. The health department support of a pilot program in the Norfolk area is a giant step. We want to see it work and we want to see it implemented across the Commonwealth.

During pregnancy, drugs or other substances which under other circumstances are safe, can cause damage to the fetus. The Action Agenda discusses what we can and must do in the area of fetal alcohol syndrome and other realted problems. Our knowledge of the kinds and amounts of substances that are harmful to developing fetuses is constantly expanding. Few physicians, much less consumers, can keep up with all the research on the possible effects of substances on the unborn child during pregnancy.

Consequently, there is not a good system for alerting women to whether a drug they are using is safe. Virginia needs a hotline that doctors and patients can call to find out what is currently known in order to protect unborn babies from harm. In addition to that service, a hotline becomes an important research tool. By following patients and reporting their practices and pregnancy outcomes, the registry builds knowledge about unknown or little known effects of substances, and consequently new information and new practices are derived. Such a registry should be based at one of our medical schools and should involve the Department of Mental Health and Mental Retardation, which is responsible for substance abuse prevention.

But the most important thing of all that we can do in the perinatal period is to get women to see their doctors early and often.

III. The third focus of the Action Agenda is on early childhood. Here the biggest gap is the coordination of services to disabled children and children at risk under the age of two. One of the most important actions we could take would be to designate a lead agency to establish a comprehensive, coordinated system for identifying and serving handicapped and high-risk children during their early years. This lead agency, during the planning phase of system coordination, would be given the responsibility and the authority to see that coordination is achieved. You have recommended that we begin a statewide lead screening program for all children at age 2 because of some ill-founded assumptions about the sites at which lead poisoning occurrs. This lead screening program, in a much broader way, would be [a major new weapon] and I am sure you will see us working on that in the very near future.

IV. Finally, there are issues that cut across agency lines and across all causes of DD. *The fourth section of your Action Agenda addresses those issues under the rubric administration, philosophy, and coordination.* Since the early '70s there have been calls for state level coordination of prevention services. It was a very strong recommendation during the 1979 prevention conference. You have asked for it again and we will continue to press for it. There should be an office of prevention at a high level of state government, and there must be coordination, not only across agency lines, but also, in our governmental system, across secretarial lines.

You have called for the increased involvement of wide varieties of community groups and individuals in prevention. We cannot look to any one

department or to government to implement the recommendations of this Action Agenda. Nor can we look only to medical professionals, educators, social workers. Developmental disability prevention requires that we collectively look at individuals and at community systems. A comprehensive and coordinated approach to prevention requires us to involve all segments of our communities. We must address the many social, political, and economic factors which cause and define DD. Agencies and groups must form new linkages and begin to work together.

Not only is a systems approach more appropriate in the resolution of the problem, it is a more powerful tool to get the job done. As strong as we are, if there are some 300 or 400 unconnected advocates for prevention in Virginia. We would be severely hampered. The effort would die aborning. Therefore, we must enlarge our power and influence through coalitions. In this way, there is virtually no limit to the number and types of groups that will join us in this common cause and to the achievements we can obtain.

Another benefit of the systems approach is the one I alluded to earlier, and that is the development of a strong political constituency for prevention. We will not achieve the goals of the action agenda unless we dramatically increase our political awareness, maintain our credibility,and press our case. We must enter the politial arena and this is a major task of the prevention coalition.

The Action Agenda shows us the way. I said earlier that we are nearing the end of our conference. Let me assure you we are just beginning our quest.

State Panel Summaries

The Basic Infrastructure of Prevention

by Joseph J. Bevilacqua, Ph.D.
Commissioner
Department of Mental Health and Mental Retardation

I am going to be very direct. I have three major points, and I am going to be somewhat sharp in my comment on the Action Agenda; sharp in a sense that my comments will reflect my biases, and as I sit as Commissioner, there are some advantages to having biases.

One point is what I call a state-of-mind problem with the document. I notice that some of the revised language has begun to broaden the base, but my concern is that there is a social-dimension aspect to this document that is missing. Someone had mentioned on the question of the biomedical versus behaviorial dichotomy that there had been too much of an emphasis on the biomedical. Dr. Tarjan mentioned this whole question of nature/nurture. My sense is that we have spent time talking about some of the biomedical aspects and not enough time on what I call basic infrastructure of support services, housing, nutrition, transportation, and home visiting. I would hope that this Action Agenda tackles that issue directly because one of the problems of the South has been the lack of this social support infrastucture. I think the notion of the clinic-based practice model that is being taken over not only by the private practice of medicine, but also many of our social welfare aspects, is a serious impediment to the kind of action this conference is attempting to direct.

Secondly, what I call the coalition connection has to be articulated more directly. It is not enough to mandate legislation, it is important to understand how legislation is made and the relationship of legislation to the bureaucracy. It seems to me that an action plan has to articulate that much more directly than this document does. I think it begins to acknowledge the bureaucracy of agencies, the governor's office, etc., but it needs to be sharply drawn as to how we can move to an end product of a rule or a law or a regulation to engage the levels of government that have to be engaged.

Thirdly, and perhaps most significant, there is very little language in the document about budgeting. There are some calls for more money, but

there is no conversation in this document on how we will address the question of budget. Dr. Moser made a profound point when he cautioned us not to set up competition between prevention activities and service activities. I think the way we are structured to develop budgets--each department identifies by line item specific issues and takes them through the system--is no longer adequate to deal with this kind of issue. We have made it very clear that the question of prevention is a connecting activity owned by no one agency and no one sector. When it comes to budgeting, we are very stupid as to how we present those requirements. What I am suggesting is that we need to think anew how we will identify that process for the resources we need. That means that Jim Kenley or Bill Lukhard or Joe Bevilacqua asking for a program item with a specific dollar amount attached may no longer be the way to do it. We may need to think of attaching a dollar figure to the need that we identify, not to the boundary of an agency.

This is particularly important now with the states assuming more and more responsibility in managing and directing these programs. I think the bureaucracy needs to hear from the total field how we should begin to examine that question.

And finally, regarding ethical issues, it seems to me that if we can deal with these very personal, profoundly individualistic issues we ought to do a better job with the resources that are necessary. So, in summary, the social dimension needs to be sharpened. The coalition connection needs to be sharpened, and we do need a reexamination of how we ask for the resources that are necessary.

Call for Cooperative Educational Program

by Nathan G. Tubbs, Ed.D.
Administrator for Special and Compensatory Education
Department of Education

I am delighted to be here this morning because I believe that this is a most important topic, and it is difficult, if not impossible, to support all of the recommendations in the preliminary agenda.

I would like to point out some of those that we in education either have a particular interest in or are involved in heavily already. These are screening for the newborn, teenage pregnancy, and perinatal care. Obviously, we are also heavily involved in the entire area of early childhood education and related services, and so I will not speak to those issues at this point. I would like to say just one word about the matter of child abuse. As you know, teachers, particularly, are charged with responsibility of identifying and reporting suspected child abuse cases,

but I would suggest that there need to be more precise communication linkages and action linakges between the courts and the schools in order to adequately address this particular problem.

By means of a task force, we have been working for the last three years on interagency coordination. This has now been given basis in the code and, incidentally, a title change to the Interagency Coordinating Committee. Education has been heavily involved with other appropriate agencies in planning a collaborative approach to service delivery at the state and local level, so obviously we are interested in the comments and the action plan related to early screening, the transfer of information, and referral. We think this is not just important, it is critical.

I do believe that public education has made tremendous strides in identifying handicapped children, although we know that there are still handicapped children out t. e who are not being identified soon enough and some who are not being identified at all.

I do not think that educators, school superintendents, and their staffs have always been succesful in coordinating and communicating their programs and services with other agencies. But I do not think that school superintendents stand alone in this regard. I call on all of the local agencies to establish these vital communication links. We do know that early intervention works. While we have no statistical research findings to support this claim, we have been heavily involved in early childhood education and do have case histories that show early intervention does work.

I am intrigued by the idea of increasing our involvment the private sector in this effort. I believe that by setting up lines of communication with private pediatricians, we may close the gap that exists in identifying handicaps early on. I am rather pessimistic about "shotgun" approaches to educating the public in public health matters via the media--specifically prenatal and perinatal care. I would, however, suggest that we approach employers in business and industry to enlist their aid and to convince them of the practicality and value of cooperative programs which are designed to educate their employees in such matters.

With regard to services for high-risk handicapped children, birth to school age, I would like to endorse the first recommendation, support for a lead agency, to facilitate comprehensive planning. This could come out of the Interagency Coordinating Committee which is mentioned in Recommendation 4 under that section.

I am particularly interested in Recommendation 3, and I call for a cooperative educational program emanating from within my own agency, the Department of Education, and extending to other state agencies composed of special educators, health educators, and adult evening educational programs, in an effort to develop programs for parents and prospective parents.

Finally, there may be a need for code change, a new section in the code for clarifying statements that would read somewhat like this, "that any agency, physician, hospital, or other health care professional who identifies a child suspected of being handicapped, be required to report such incidence to the local division superintendent or health director for appropriate evaluation."

I do not believe that we have fully tapped the human potential for creative productivity, as well as for living a satisfying life as a contributing member of society. This can only come about if we have effective educational programs, and high quality support programs in terms of physical and mental well-being. I would like to note, however, that all these programs will be severely limited and constrained if we do not have a healthy infant at the start.

Care Needed Among High-Risk, Uninsured Prenatal Group

by James B. Kenley, M.D.
Commissioner
Department of Health

Having just finished a tour of Russia and China, I came back with a sense that we Americans are a very assertive and aggressive people and we have created a life here that has many aspects other countries have not had. We are fiercely competitive, but can be only because we are compassionate and care for each other. I believe you demonstrate that here today. I would like to mention several individuals who will help me in the Central Office to work on this plan for action, Dr. Hunsacker, Dr. Alice Linyear, and, of course, Dr. Bedford Berry, who heads up Family Health Services.

I would like to add to Dr. Elder's remark and say "amen" to Dr. Bevilacqua's because those are very important things for us to get anything done with every change of administration, the decision makers in those centers move around. Just about the time we have lost a good friend who cares for the same concerns we have, another one appears on the horizon, but we have to recognize them. We experience in this state very similar things that you express at the federal level.

Let me talk a little bit about the 1960s because when I first came to Virginia, my second assignment was over in the Valley. A public health nurse came back one day and told me about a young mountain couple quite a distance out who had just come home from the hospital with their baby who had spina bifida. I found that was not covered by the crippled children's program. The reason why it was not covered: there was not much potential. That did not quite make sense to me. Why should we send this baby home to die? Could not we do more than that? It was at that time I started bombarding Central Office to re-examine that policy and, in the meanwhile, we got the baby back into the hospital. Fortunately, it was at a time when we were beginning to feel the results of the Salk vaccine polio programs and what I am saying is that money became available for us to move ahead.

I say this because with history, we must be aware that those of us who are here now will be around a long time and will be part of history and change, and the young ones who follow have the right to start from those points of change. It is toward that level of expectation that we must move. Before we deal with budget considerations at the state level, you have to know what the system is, how it works, and what is next, because this matter of the targets that we are given is rigid--it reminds me of a toy my boy got for his birthday, a little kiddie stool in which he inserted a block, hit it with a hammer, and another block jumped out. That is the way it is with our budget today. I refuse to water down all the programs I have to the point where we do not accomplish anything, and that is what you do when you give in to a cut here, a cut here and an across-the-board cut.

Remember there is another important group that shares disabilities; the elderly population that is increasing in numbers in our state and country. The elderly have many needs that often require adequate and continuous funding, so we have to work with that group, too.

I would like to point out one problem that we can try to change through our health insurance system; often the group that is high risk has no coverage for prenatal care. It concerns the adolescent who works and has Blue Cross/Blue Shield, Aetna, or other coverage, but because of a clause that she has to be married nine or 12 months, she is often not covered. Do you know that among the teenagers who do marry, half of them are already pregnant? This lack of coverage is something that concerns me in these new competitive systems that are developing. Watch those, there are going to be more gaps in coverage for the groups that we are talking

about today then there have ever been before. You are going to be shocked because high-risk people are going to be deleted from insurance plans, and it is going to leave us, the social agencies, state agencies, state government with very high-risk group needing expensive coverage.

It is very important that we maintain investigative capabilites at the state level. In relationship to lead poisoning, we are finding now that little children do not get lead just from eating plaster and paint within their home, but we find that it is in the soil and in new dwellings, particularly in water that has been standing in the pipes in the home overnight. We are investigating that now.

That gives you some idea of really what we need to do to continue moving forward. With this marvelous plan, working together, we can expect steady improvement even in tough times.

Marketing Prevention

by William L. Lukhard,
Commissioner
Department of Social Services

Many of you, I am sure, have read the bestseller, *Megatrends,* in which John Nesbitt identifies one of our major trends as self-help, and certainly prevention is a very, very important aspect of self-help. Prevention hits us every day, when we turn on the television or pick up a magazine. So I do conclude that your convention, and the idea for prevention, is really timely and I think we now need to capitalize on it.

The state Board of Social Services and the state Department of Social Services provide a broad range of programs to serve a broad range of target populations. Our programs touch children, families, the elderly, the physically handicapped, the developmentally disabled, the economically disadvantaged, and so on. We are in the process of trying to reprioritize, also; that is, to group our programs into three areas making prevention a top priority, intervention a second priority and only when necessary, and, finally, substitute care, only where it is in the best interests of a child or the individual adult. What we find, of course, is very few dollars going into prevention and a tremendous amount of dollars going into substitute care and into intervention.

In endorsing the conference and in offering continuing staff assistance to follow-up on the recommendations of the action plan, I would also like to highlight some ways the Department of Social Services could be involved in implementation of the plan.

First, I see us involved in the marketing concept. For example, monthly we issue some 60,000 checks to ADC families; certainly bulletins or brochures to deal with certain subjects could accompany those checks. People are now used to reading additional material that comes with their check or bills. I think that with 124 local departments of social services, one in each county and city in the Commonwealth, these are places that posters and pamphlets can be utilized in waiting rooms to which people could be exposed. More importantly, in those agencies, our helping professionals should be trained to be advocates in the client's behalf, particularly in the low-income areas. A client should be told of all the services available, not just what he asks for. Locally, I think there could be an interagency speakers' bureau to help educate people about the risk of certain activities, and certain high-risk populations could be targeted as the priorities for these.

A fresh look should be taken at interagency staffing and interagency training. There might be conferences similar to this one held in the localities that could result in local action agendas. These things that I have mentioned are just the tip of the iceberg. But at least we need to get started, and then we will see additional ways in which we can increase prevention efforts.

Currently, the department is involved in some prevention efforts, and I think the Commonwealth of Virginia has coordination among its agencies that the general public does not appreciate. I do think that we are cooperating--we have contracts under Title 20 with the Department of MH/MR for substance abuse, with the Department of Health on family planning, and with the Department of Rehabilitation Services for social services at Woodrow Wilson. Through our regular protective services program, we find cases of abuse and neglect and intervene to prevent the family situation from futher deteriorating. Through the Title 20 social services block grant, the Virginia Board of Social Services has allocated $250,000 per year for preventive protective services. The 1982 session of the General Assembly raised the marriage license fee $7, and out of that we have as a department $375,000 per year for domestic violence grants. We have funded a number of projects aimed at reaching high-risk families before the parents become actual abusers. A major emphasis in this area is on parenting education. Local Chapter 10 boards have been involved with these grant programs, and while the source of these programs and the funds are not large, I think they are fairly stable for the moment.

The other major resource within the Department of Social Services that I can see being used for prevention concerns the Neighborhood Assistance Act. The purpose of the act was to involve the private sector in helping address the needs of low-income individuals. While the program does not provide funding per se, it does provide a state income tax credit of 50 percent to businesses that contribute either cash or in-kind to an approved project. The department's role is approving the project.

Some of our current projects benefit the mentally retarded and the developmentally disabled, but none of them is geared toward prevention. To give you an idea, the tax credit for this fiscal year is something like $3.5 million. That would engender $7 million for programs that would meet the criteria of the act.

We do have some very exciting projects going on, but I do think there is real potential to use this program for prevention efforts, and I would encourage you to contact the department if you desire to provide additional information.

I cite these special funding sources because, like Drs. Bevilacqua and Gallagher, I am concerned that the traditional public funding source of taxes is not a resource at this time. When you look at the practical political environment, tax dollars will be limited. Those dollars traditionally have gone to what I call crisis funding. Legislators always say, "That is a fine idea on prevention, how much will it save?" What I have had to tell them is that you cannot take it immediately from an ongoing program. It has got to be an investment, it is cost avoidance down the road. I think with an action agenda that is endorsed by a number of groups, we might have a better chance, but in this day of constraints, I think we have to look at the political reality.

In closing, let me challenge all of us in the room to make the implementation of the Action Agenda as exciting and coordinated and determined as the writing of it.

Call for Coalition

by Gary Hammer, Ph.D., President
Association for Retarded Citizens

I think you all noticed, as I have, that we have seen and heard these past few days a hall of fame of prevention pioneers, folks who have labored long in the vineyard for prevention of mental retardation and developmental disabilities--what I am going to call now a gallery of spark-strikers. What I want to say to Dr. Tarjan, Dr. Boggs, Dr. Guthrie, Dr. Moser, and to the others is that those sparks that have been floating around out there for a long time have found dry tinder here in Virginia. I think the tinder is smoking, and this convention and ARC-Virginia wants to blow on it some more to make sure that the flame really lights. Our convention slogan is, "Give us an inch and we'll go the mile." I am satisfied that we have come a good bit longer than an inch these three days and, as Peter says, we *are* running. ARC-Virginia wants to make sure

that we go that second inch, that we run a little farther, that we pull back on the stick of that 747; so we are going to take the lead, and we are going to organize or formalize a coalition by calling a meeting early in January to make sure that the plan of action is in fact put into action. Thank you.

Closing Address

by Peter Mamunes, M.D.
Albert Einstein Medical Center
Philadelphia, Pennsylvania

In Virginia we have come an awesomely long way in the field of prevention of MR and DD since I first came to the state to work in the field of pediatrics, genetics, and metabolism in 1969. At that time, virtually none of the present prevention programs existed. Over the ensuing years, I have actively participated in or intimately witnessed the development of many of the present services vital to the prevention of the biomedical causes of MR and DD. Virginia was one of the first states to have Tay-Sachs screening available at the community level. It received one of the most substantial early grants from the federal goverment for the delivery of statewide coordinated genetic services, including prenatal studies. With the recent passage of legislation to expand neonatal screening to metabolic disorders, it has one of the best such programs in the country. And how refreshing to hear the governor himself publically espouse support for screening for a disorder which occurs only once in 225,000 births. That in itself was worth the trip from Philadelphia.

Virginia has also instituted significant programs in many other areas too numerous to count. Just to mention a few: a nice new prevention office, birth defects registry, fetal alcohol prevention, lead screening, education of groups at risk for child abuse, accident prevention, adolescent sexuality, and, of course, the whole program of developmental disabilities and rehabilitation.

The real question is, where do we go from here? I have carefully listened to all of the presentations and fully support the many imporant suggestions made regarding the implementation of the Action Agenda presented to you today. It is especially important to develop a state body, call it a commission or what have you, to coordinate the many state agency programs in prevention activities. During my many years of involvement in this state, I came to have very high regard for the desires and motivations of the agency heads in regards to implementation of prevention programs. On the other hand, the realities of the budgetary processes of state agenceies, as you have heard, clearly dictated the need to seek support from the legistature for various programs. I especially

appreciated Dr. Guthrie's recommendation that prevention legislation should be ordinary business "like schools and highways." For this purpose a coalition of consumer advocates is a must.

We have indeed come a long way, but we have as yet an unbridled potential. I mean to say that, in all of my years of exposure to the services in the state and having trained and practiced in several other states, Virginia is well-heeled with excellent people and programs. We need to bridle, to build on our strengths and address the new issues that we have before us. I believe that the best way I can convey to you my feeling of where we are with prevention at the present time is to liken it to an airplane takeoff.

I chose this example because most of you have gone through this experience. For the last 15 years, 747 jumbo jets have been rolling down the runway, ever faster, gathering speed to soar off into the bright blue, promising sky. Please do include on this trip, as Dr. Bevilacqua admonished, clearly delineated goals for the prevention of the 80 to 85 percent of those who are mildly retarded, due in a great part to the sociocultural and the socioeconomic factors.

I am truly thankful to Drs. Gallagher and Mercer for educating me in these needs that I was not as appreciative of before. Clearly prevention's time has come; it is up to each of you to take advantage of this marvelous running start that this conference has provided.

Biographical Summaries

Gordon B. Avery, M.D. Ph.D., a graduate of Harvard University and the University of Pennsylvania, is currently professor in the Department of Child Health and Development at George Washington University School of Medicine and Chairman of the Division of Neonatology and Children's Hospital National Medical Center, Washington, D.C. He is a pediatrician specializing in neonatal/perinatal medicine. Dr. Avery consults extensively for such centers as the Bethesda Naval Hospital and has many publications to his credit.

Allen C. Crocker, M.D., is associate professor of pediatrics at the Harvard Medical School, senior associate in medicine at Children's Hospital in Boston, and director of the Developmental Evaluation Clinic at Children's Hospital. Dr. Crocker has been a prolific researcher, vitally interested in the quality of service delivery systems. He has served on the board of directors of: the May Institute for Autistic Children, Project Impact in Boston, the Center for Creative Art Therapies in Boston, Adaptive Environments, the National Down's Syndrome Congress, the Special Olympics sponsored by the Kennedy Foundation, and the American Association of University-Affiliated Programs for Persons with Developmental Disabilities, of which he is also past president. He has also served on the editorial advisory board of *Exceptional Parent*.

Jean K. Elder, Ph.D., is the commissioner of the Administration on Developmental Disabilities for the Department of Health and Human

Services. She received her master's and doctorate degrees in psychology at the University of Michigan and completed post doctoral work at the University of Wisconsin. An educational psychologist, she was associate professor at Michigan State University and at Northern Michigan University. She is author of numerous articles in the fields of developmental disabilities, mental retardation, and special education, and has lectured widely. Dr. Elder was appointed to the President's Committee on Mental Retardation by President Ford. In 1968, she was elected a Fellow of the American Association on Mental Deficiency. She is an active member of numerous organizations, including the Association for Retarded Citizens and the Council for Exceptional Children.

James J. Gallagher, Ph.D., is the director of the Frank Porter Graham Child Development Center in Chapel Hill, North Carolina, and professor in the School of Education, University of North Carolina at Chapel Hill. He attended the University of Pittsburgh and Penn State for his master's and doctorate degrees in child and clinical psychology. He has served as associate commissioner and deputy assistant secretary in the U.S. Office of Education. Dr. Gallagher has received numerous awards from: the Association for Children with Learning Disabilities; AAMD; the John Fogarty Award for government service; and the Rollin award from the Council for Exceptional Children. He is author of numerous articles. He has held offices including the presidencies of the World Council for Gifted and Talented Children and the Council for Exceptional Children and the chair of the Social Policy Committee for the Society of Research in Child Development.

Robert Guthrie, M.D., Ph.D., is professor of pediatrics and microbiology at the State University of New York at Buffalo. He is the principal developer of PKU screening techniques. He has actively promoted federal legislation providing assistance for the initiation and expansion of the Children's Preventive Health Programs, including expansion of neonatal screening programs for inborn errors of metabolism and lead poisoning screening programs for preschool children. Recently, he has been working to form a national group of parents of PKU children and to establish a Western New York Task Force for the prevention of mental retardation and developmental disabilities. Dr. Guthrie has assisted China and other underdeveloped nations in initiating newborn screening for inborn errors of metabolism. He has received many awards from: The American Association of Mental Deficiency, the American Academy of Mental Retardation, the Association for Retarded Citizens, the Pool of Bethesda Award, and the Kimball Methodology Award.

Peter Mamunes, M.D., is chairman of the Department of Pediatrics at the Albert Einstein Medical Center in Philadelphia. He received his doctor of medicine degree from the College of Medicine of New Jersey, Newark, and has held academic appointments at Temple University School of Medicine and the Medical College of Virginia. He is a member of the American Society of Human Genetics and American Society for the Advancement of Science, a diplomate of the American Board of Pediatrics, and a founding member of the Society for Inherited Metabolic disorders. While at the Medical College of Virginia, he co-directed the Tay-Sachs screening programs and the genetic counseling clinic, served as consultant to the Virginia Health Department in PKU and other inborn errors of metabolism, and established MCV as one of the 20 centers in the country for dietary treatment in inborn errors of metabolism.

Jane R. Mercer, Ph.D., is professor in the Department of Sociology at the University of California at Riverside. A prolific researcher, she receives support from agencies and institutions such as the National Institute of Mental Health, the Office of Education in the Department of Health and Human Services, and the State of California. She is very involved in defining the problems of mental retardation and other development disabilities and has had extensive public service in that area. Dr. Mercer is the author of a significant number of books and articles.

Hugo W. Moser, M.D., received his doctor of medicine degree, with a specialty in neurology, from Harvard University. From 1965-1976, he was associated with the Walter Fronoud State School in Massachusetts. He is currently director of the John F. Kennedy Institute for Handicapped Children and professor of neurology and pediatrics at Johns Hopkins University in Baltimore, Maryland. He is a member of the American Academy of Neurology, the American Association on Mental Deficiency, the American Association of Neuropathologists, the American Academy of Mental Retardation, the Maryland Society for Medical Research, and the American Society for Cerebral Palsy. In 1982, he served as president of the American Academy of Mental Retardation.

Godfrey P. Oakley, Jr., M.D., is chief of the Birth Defects Branch, Chronic Diseases Division, at the Centers for Disease Control in Atlanta, Georgia. He is also a diplomate in the American Board of Pediatrics. He

received a master of science degree in preventive medicine in the field of public health services from the University of Washington and his doctor of medicine degree from the Bowman-Gray School of Medicine. Involved in genetics nationally and internationally, Dr. Oakley has served on the Genetics Committee of the Georgia Department of Human Resources and the Genetics Coordinating Council of the National Institute of Health (CDC). He has written numerous articles.

George A. Tarjan, M.D., professor in the Department of Psychiatry and Behavioral Sciences at the UCLA School of Medicine, is one of the leaders in the field of mental retardation. He has received the Leadership Award of the American Association on Mental Deficiency; the Kennedy Foundation International Aaward for distinguished leadership in the field of mental retardation; the Award of Merit from the President's Committee on Mental Retardation; the Distinguished Serivce Award from the American Psychiatric Association; and the Award for Distinguished Service to Mentally Retarded Citizens from the Exceptional Children's Foundation. Among the organizations he has served as president are: the American Psychiatric Association, the American Association on Mental Deficiencies, the Groups for the Advancement of Psychiatry, and the Southern California Psychiatric Association. He is a fellow in the American Academy of Child Psychiatry, College Psychiatrists, and the American Psychiatric Association.

Keynote Speakers At A Glance

George A. Tarjan, M.D.

James J. Gallagher, Ph.D.

Robert Guthrie, M.D., Ph.D.

Jean K. Elder, Ph.D.

Jane R. Mercer, Ph.D.

Godfrey P. Oakley, Jr., M.D.

Peter Mamunes, M.D.

Gordon B. Avery, M.D., Ph.D.

Allen C. Crocker, M.D.

Hugo W. Moser, M.D.

Special Award Conferred

For her "professionalism, personal commitment, and tireless effort," Dr. Ruth Diggs received a commendation from Governor Charles S. Robb during a surprise presentation at the conference. The commendation reads, in part: "During her distinguished career in special education, Dr. Diggs has been a tireless advocate for the prevention of mental retardation and other developmental disabilities. Dr. Diggs recognized years ago the need for higher education to play a leading role in prevention and has worked on the national, state, and local levels to achieve this goal. Dr. Diggs is honored here by fellow Virginians for her vision, creativity, and enthusiastic efforts to improve the quality of life for mentally retarded persons in Virginia and the nation."

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Afterword

An evaluation form was included in the packets of the conferees, and a request to complete the forms was made at the last session of the conference.

The instrument recorded satisfaction with individual workshops and general sessions, as well as overall opinions of the conference.

The scale for evaluation was 1 through 5 (1 indicating "not helpful" or negative comment, 5 indicating "very helpful" or positive comment). All workshops averaged out at 4.0; all general sessions averaged out at 4.15. More than 100 evaluation forms were collected.

The evaluations strongly support the importance and quality of the conference. General comments were overwhelmingly positive and appreciative of the efforts of the planning committee. Some complaints were received about physical comfort (rooms too cold, hearing problems, etc.), but genuine appreciation was expressed for the barrier-free facility.

The evaluations reflected a feeling of optimism and a belief that MR/DD Prevention has now become a reality in Virginia.

The Beginning

A meeting was held on March 8, 1984, to develop plans for a statewide coalition for the prevention of MR/DD. A statewide coalition will be formed by July 1, 1984.

The Action Agenda is currently being analyzed by government and private sector groups to plan and implement MR/DD Prevention efforts.

Virginia's medical schools are working together towards efforts in research of causes of MR/DD.

State agencies and private sector groups are focusing energies on specific causes of MR/DD and developing public awareness campaigns.

MR/DD Prevention is a reality. What is needed NOW is vision, courage, and faith.